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THE UNIVERSITY OF ALBERTA

PARENTAL GRIEF FOLLOWING THE LOSS OF AN INFANT IN NICU

BY

(C) SHARON MORGAN

A THESIS

SUBMITTED TO THE FACULTY OF GRADUATE STUDIES AND RESEARCH

IN PARTIAL FULFILLMENT OF THE REQUIREMENTS FOR THE DEGREE

OF MASTER OF NURSING

FACULTY OF NURSING

EDMONTON, ALBERTA

FALL 1987

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(Signed) Sharon Morgan

228 Hawkcliff Way N.W

Calgary, Alberta

Date: May 28, 1987

THE UNIVERSITY OF ALBERTA

FACULTY OF GRADUATE STUDIES AND RESEARCH

The undersigned certify that they have read, and recommend to the Faculty of Graduate Studies and Research for acceptance, a thesis entitled "Parental Grief Following the Loss of an Infant in NICU" submitted by Sharon Morgan in partial fulfilment of the requirements for the degree of Master of Nursing.

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(Supervisor)

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Date: May 26, 1987

DEDICATION

This is dedicated with gratitude to the parents who participated and who taught me so much.

It is dedicated with love, to my brother Jack and to my family, who shared with me, his loss.

Abstract

The purpose of this exploratory, descriptive study, was to examine the nature and duration of grief experienced by parents over time, following the loss of an infant in NICU. In particular, the focus was on the degree to which parents felt their grief had been resolved, the meaning of resolution to parents and the lasting remnants of grief that remained once resolution was percieved to have occurred.

Seven couples who had experienced the loss of an infant in NICU were selected. Four couples were one to three years post-loss and three couples were five years post-loss. Data were collected using a semi-structured interview guide and the Texas Revised Inventory of Grief. Verbatum transcripts of the interviews were subjected to content analysis to determine parents' perceptions of the events that surrounded their infant's death, their degree of resolution, the changing nature of their grief over time and the lasting thoughts, feelings and perceptions they were experiencing at the time of interview.

All of the parents believed their grief had reached the point of resolution, although the exact meaning of resolution differed between the parent groups. Parents at five years post-loss were able to describe to a greater degree, several elements of the experience of loss and grief that remained even after grief had been resolved.

These lasting remnants of grief were developed into a schema which included primary and secondary remnants of grief. Primary remnants were: grief itself, vulnerability, cognitive residuals and affective residuals. Secondary remnants included lasting impressions of: the events surrounding the loss, the caregivers, the self-image as parent to the lost infant and the infant. Using this schema, a new conceptual model for the resolution of grief was proposed.

Based on the findings of this study, a number of important questions were raised for nurses who work with parents prior to and following the death of an infant in NICU. In addition, several questions for further research were generated.

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I would like to express my deep appreciation to all of those who have given me their support and guidence through the completion of this study. First, I would like to extend my sincere thanks to each of the parents who participated for their unguarded openess in sharing their experiences and feelings. Without them, this would have been impossible.

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When it comes to caring and friendship, I have always believed - "don't say it, show it". I would like to thank all of those who have "shown" me. I would especially like to thank the following people: Nola, for her friendship and hospitality as I worked "long-distance"; Jamie for

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CHAPTER I

STATEMENT OF THE PROBLEM

Introduction

The death of a newborn has been described as a catastrophic event and a source of profound and prolonged grief for parents (DeFrain, Taylor & Ernst, 1982; Condon, 1986; Hagan, 1974; Hagan-Arnold & Gemma, 1983; Kennel, Styler & Klaus, 1970; Kirkley-Best & Kellner, 1982; Kowalski, 1980; Quick, 1974). Parental bereavement has been studied in relation to miscarriage (Corney & Horton, 1974; Stack, 1980), stillbirth (Bourne & Lewis, 1984; Kirkley-Best & Kellner, 1982; Lewis & Page, 1978; Lewis, 1979; Wolff, Nielson & Schiller, 1970), sudden infant death (DeFrain et al., 1982; Krein, 1979; Lewis, 1983; May & Breme, 1982) and loss within the neonatal intensive care setting (Forrest, Standish & Baum, 1982; Giles, 1970; Kennel, Styler & Klaus, 1970; La Roche, Lalinec-Michard, Englesmann, Fuller, Copp, McCade, Soldatos, & Gzima, 1982, 1984; Mahan, Perez, Ratcliff & Schreiner, 1981; Rowe, Clyman, Green, Mikkelsen, Haight & Ataide, 1978). There is a substantial body of research which has validated the existence of parental grief and demonstrated that the majority of parents suffering perinatal bereavement undergo the classic physiological, psychological and emotional patterns of adult grief described by Bowlby (1980),

Lindemann (1944), Parkes (1965, 1972), Parkes and Weiss (1983) and Raphael (1983).

The majority of research on perinatal bereavement has been conducted within the first one to two years following loss. Research efforts to date have shed substantial light upon the initial needs and grief experience of these parents. In addition, this body of work has given important direction to the care and support of bereaved parents in the period immediately following loss. It is critical to note, however, that little has been documented about the experience and needs of parents beyond the first one to two years. Clinical experience and a limited amount of research suggests that the years subsequent to this initial period of bereavement may continue to be difficult for parents who have lost an infant (Berezin, 1982; Edestein, 1984; Hagan-Arnold, 1983; Kerner, et al., 1979; La Roche et al., 1984; Peppers & Knapp, 1980; Rando, 1983, 1984; Rubin, 1981; Shandor Miles, 1985; Wolfe et al., 1970). There is further evidence suggesting that failure to come to terms with and resolve the loss of a newborn may have serious implications for the individual parent, the marital relationship, other parent-child relationships and the well-being of the family as a whole (Bourne & Lewis, 1984; Bowlby, 1980; Cain & Cain, 1964; Condon, 1986; Drotar & Irvin, 1979; Hagan-Arnold & Gemma, 1983; Helmrath & Steinitz, 1978; Johnson, 1984; Kerner et al., 1979; La

Roche et al., 1984; Lewis & Page, 1978; Lewis, 1983; Rando, 1980).

There is general agreement in the literature that the normal process of grief progresses to a point of resolution and recovery. However, there is great variation in thought as to how long resolution actually takes, and perhaps more importantly, what constitutes resolved versus unresolved grief (Bowlby, 1979; Carr, 1985; Glick, Weiss & Parkes, 1974; Lazare, 1980; Parkes, 1972; Parkes & Weiss, 1983; Raphael, 1983). Nonetheless, most researchers designate the first one to two years as the point at which normal resolution occurs. Unfortunately, few studies have focused in a systematic way on the duration of grief or the nature of the grief experience as it changes over time. Too often, long-term studies of the grief process have been oriented towards the extreme pathological rather than non-pathological sequelae of grief.

In light of the above concerns regarding the long-term difficulties of bereaved parents and the serious implications associated with unresolved grief for this unique group, it is critical to gain a better understanding of the projected grief experience and the lasting sequelae of loss. Several questions arise: What is the grief experience of parents beyond the first one to two years post-bereavement? What can be determined about the resolution of grief in the years that follow this initial

bereavement period? What does the resolution of grief mean to parents? and, finally, What are the lasting thoughts, feelings, perceptions and concerns of parents following the loss of an infant?

These questions must be examined in order to fully understand the dimensions of the grief experience and the factors which promote or inhibit a positive outcome for bereaved parents. Furthermore, the answers to these questions have important implications for nurses who seek to provide compassionate and capable care to bereaved parents in both the acute care and the community setting.

Definition of Terms

The phenomenon of grief has been studied with increasing interest over the past few decades. Within the literature, the terms grief and mourning have been used interchangeably although some writers, such as Bowlby (1980) and Raphael (1983), make clear definitional distinctions between these concepts. Whatever words one chooses to use, the phenomenon under study is the human response to a significant loss. The concepts of grief, mourning and resolution are complex and multidimensional and are, by their very nature, difficult to define in operational terms. For the purposes of this study, the following conceptual definitions were adapted from the literature.

Bereavement - A situational phenomenon occurring as a result of the loss of a close and important relationship.

Grief - The emotional, physiological and psychological response to loss.

Mourning - A process that involves coming to terms with, accepting and adapting to loss.

Resolution - The end of mourning. The point at which one has come to terms with, accepted and adapted to loss.

Purpose

The purpose of this study was to examine the nature and duration of grief experienced by parents at one, three and five years following the death of an infant in NICU.

Research Questions

The following research questions guided the study:

1) To what degree do parents at one, three and five years post-bereavement feel they have resolved their grief?
2) If parents perceive their grief to be resolved, what are the lasting feelings and perceptions related to their loss?
3) If parents perceive their grief to be unresolved, what are the lasting feelings and perceptions related to their loss?
4) What is the pattern of grief observed at one, three and five years following the loss of an infant in NICU?

CHAPTER II

REVIEW OF THE LITERATURE

The Grief Experience

In the past, grief and mourning have been poorly understood and often studied from a perspective of psychopathology and maladaption. More recently, grief and mourning are perceived primarily within a normative framework. Gullotta (1982) is one of many who argue that grief, sorrow and mourning are natural processes. In like fashion, Brice (1982) has conceptualized grief and mourning using Erikson's theory of developmental stages. Brice suggests that grief is a moveable, developmental phenomenon which arises periodically over the lifespan.

Lindemann (1944) was one of the first to systematically study and document the initial reaction to bereavement. He described a "remarkably uniform" pattern of responses in 101 persons in acute grief. He outlined a syndrome which included a variety of sensations: somatic distress, intense, subjective distress, pre-occupation with images of the deceased, hostility and changes in patterns of normal conduct. According to Lindemann, grief work is the process of breaking bonds with the deceased, readjusting to an environment from which the deceased is missing, and the forming of new relationships. The findings of Lindemann's pioneer work in the area of

bereavement have been supported and expanded over the ensuing decades. Bowlby (1980), Parkes (1972) and Parkes and Weiss (1983) have described a similar pattern of the grief experience; however, they suggest that grief is the process whereby the bereaved person attempts to regain and maintain the attachment to the loved one. These researchers believe that through this process, the bereaved come to realize that their loss cannot be regained and begin to adjust to life without the loved one.

The efforts of researchers and clinicians such as Bowlby (1980), Glick, Weiss and Parkes (1974), Parkes (1972), Parkes and Weiss (1983) and Raphael (1983), have contributed to the development of a greater understanding of human grief and mourning and of the factors which impact upon these processes. Research has shown us that grief is not a fixed state, nor is it marked by a rigid progression through a series of predetermined stages. Rather, as Parkes (1972) suggests, grief is a powerful, dynamic reaction to loss. Grief is characterized by a number of interwoven emotional, psychological, physiological and social responses that vary with the unique experience and style of each individual. Further, it is recognized that mourning is a process of letting go and re-ordering; a complex phenomenon whereby one moves in and out of shock, pain, disbelief and disorganization to a point where there is, at last, a form of adjustment, re-organization and

resolution.

The Significance of Parental Grief

Today, there exist greater insights than ever before into the complex phenomenon of grief. Yet, there also exists within society, a philosophical conflict regarding the impact of an infant's death upon the parent. Changes within individual life styles, the family system and society as a whole have led to a reduction in the number of infants born each year. As parents have fewer children to love and nurture, each wanted child has become all the more special and important.

In view of the increased valuing of the infant and child within society, it is both interesting and disturbing to note the "devaluing" that takes place when infant death occurs. The literature repeatedly identifies a tendency of family, friends, society and professional caregivers to deny and/or minimize the impact of and importance of both infant death and parental grief (Canadian Pediatric Society, 1983; Condon, 1986; Cordell & Apolito, 1981; Giles, 1970; Helmrath & Steinitz, 1978; Kennel, Styler & Klaus, 1970; Lewis & Page, 1978; Peppers & Knapp, 1980; Rando, 1984; Rowe et al., 1978). Yet as it was mentioned earlier, those who have studied perinatal bereavement have found the grief process in parents to be profound and prolonged (Davidson, 1985; De Frain, Taylor & Ernst, 1982; Edelstein, 1984; Hagan, 1974; Hagan-Arnold & Gemma, 1983;

Kennel, et al., 1970; Kowalski, 1980; Kirkley-Best & Kellner, 1981; Sanders, 1980).

Several writers have attempted to explain this apparent contradiction. Rando (1983, 1984) and Kastenbaum (1981) believe part of the answer lies in the "death-denying" orientation of North American Society in the 1980's. Raphael (1983) and Rowe et al. (1978) write that in most societies, the death of a child represents failure. De Spelder and Strickland (1982) believe that death and dying have become so institutionalized and removed from the normal events of life, members of society are no longer comfortable in the presence of the dying or the bereaved. Kirkley-Best et al. (1978) suggest that others cannot see or fathom the attachment that exists between the parent and infant before birth or during a short life. Some writers such as Lewis and Page (1978), believe the denial stems from the need to shut out the tragedy, anxiety and pain surrounding the death of an infant. Finally, for the professional caregiver, the orientation has long been one of cure (Benfield et al., 1978; Canadian Pediatric Society, 1983). Therefore, for many caregivers, the recognition and acceptance of death is also the acceptance of failure or defeat. Perhaps then, if one denies or negates the importance of infant loss and parental grief, one can also deny the sense of failure, the discomfort, the pain and the unexplainable entities

associated with infant death.

In contrast, there are those who maintain that the death of an infant or child is one of, if not the most traumatic and difficult kinds of loss to endure. The support for this view, although largely theoretical and anecdotal in nature, is compelling (Borg & Laskar, 1981; Ewy, 1980; Hagan-Arnold & Gemma, 1983; Rando, 1984; Schiff, 1977). Sanders (1979-80), one of the few who have attempted to provide empirical support for this argument, compared bereavement following the death of a spouse, child and parent and demonstrated higher intensities of grief in parents who survived their children. Those who have studied the impact of stillbirth and early neonatal loss maintain that such losses are compounded and worsened by a sense of untimeliness, injustice, guilt and failure (Brice, 1982; Giles, 1970; Kirkley-Best, et al., 1982; Rando, 1984). Rando (1984) and Turco (1981) believe that parents suffer not only the tangible loss of the child but also the symbolic losses of a part of themselves, their dreams for the future, and their role as caregiver. Finally, a number of clinicians and researchers agree that, within Western society, the failure or inability to recognize and legitimize the significance of an infant's loss has a profound and negative impact upon the parental grief experience (Helmrath & Steinitz, 1978; Lewis, 1976, 1979; Lewis & Page, 1978; Peppers & Knapp, 1980).

It has been suggested that the intensity and duration of human grief are greatly influenced by the circumstances which surround loss (Bowlby, 1980; Bugen, 1977; Parkes, 1972; Raphael, 1983). For example, sudden and unexpected death has been associated with greater intensity in the grief experience of widows (Parkes, 1972). The positive and negative aspects of the relationship between the deceased and the bereaved have been found to play a significant role in determining the course of grief (Bowlby, 1980; Parkes, 1972; Parkes & Weiss, 1983; Raphael, 1983). Sherizen and Paul (1977) cite extensive technological interventions, such as intensive care and resuscitative measures prior to death, as a factor which may profoundly affect the experience of the bereaved. For those who have experienced perinatal loss, factors such as those listed above are further compounded by the unique aspects surrounding the loss of an infant.

Peppers and Knapp (1980) compared grief responses in mothers who had lost infants through miscarriage, stillbirth and abortion and found no significant differences among the three groups. However, methodological shortcomings limit the application of these findings. Furthermore, the investigators stress that even though grief intensity does not differ, the grief experience itself may be unique to each group. In the cases of abortion, miscarriage and stillbirth, lack of a

live infant and a tangible relationship may adversely influence the course of grief (Corney & Horton, 1974; Boynton, Lecker & Wolman, 1978; Lewis & Page, 1978). When SIDS is the cause of death, parents are haunted by the aura of the unknown and the unpredictable. Suffering sensations of guilt and failure, these parents often believe themselves to be responsible for the death of their baby (De Frain et al., 1982; Friedman, 1974; Raphael, 1983; Rando, 1984). Parents whose infant has died in NICU have only known their baby within the context of a foreign and highly stressful environment (Zeanah & Canger, 1984; Klaus & Kennel, 1982) and often through the short life of the baby, the parent-infant relationship has been one of extreme ambiguity (Klaus & Kennel, 1982; Marshal, Kasman & Cape, 1982).

Some individuals may perceive that little is to be gained by comparing and quantifying human grief experiences. However, by so doing one is better able to understand, explain and legitimize the intense, dramatic and often overwhelming picture presented in cases of parental bereavement. Equally important, such an endeavor enables one to better explain and legitimize the need for further research into the area of perinatal bereavement. If one accepts the premise that parental grief following infant death is uniquely profound and intense, then one must ask is the process of resolving the grief which

follows such a loss also unique and perhaps more difficult to achieve? The answer to these questions are critical if one is to fully understand the experience and needs of bereaved parents.

Greater understanding of the grief experience is particularly important when one considers the potential hazards associated with grief itself and the failure to resolve grief over time. Problems reported include disturbances within the marital relationship, and family system (Friedman, 1974; Krein, 1979; Kerner, Harvey & Lewiston, 1979), and in present and subsequent parent-child relationships (Drotar & Irvin, 1979; Friedman, 1974; Johnson, 1984; Lewis & Page, 1978; Lewis, 1983; Poznanski, 1972). Furthermore, several studies describe the adverse effects of grief and unresolved grief upon the individual (Corney & Horton, 1974; Fredrick, 1976-77; Lewis, 1983; Pedder,1982; Turco, 1981, Zisook & De Vaul, 1983). These potential threats to the well-being of bereaved individuals are of major concern to caregivers. Given the earlier discussion concerning the lack of family and social support available to bereaved parents, it is obvious that the professional caregiver may have a key role to play in influencing the outcome of the grief experience.

The Resolution of Grief

Unfortunately, questions concerning the resolution of grief are not easily answered. It is evident from the

literature, that the aspects of the grief experience which are least well known are those which concern resolution. Rubin (1983, p. 101) argues that the long-term sequelae of loss have rarely been studied in a systematic fashion, "how long the response continues, the full nature of the response and the ultimate intrapsychic and behavioral consequences of adult loss have yet to be fully mapped out". This view is in agreement with other researchers such as Rando (1980, 1983, 1984), Sanders (1979-80), Shandor-Miles (1985) and Zisook, De Vaul and Click (1982, 1983).

As stated previously, a fairly consistent picture of the grief response has emerged from the classic works of Bowlby (1980), Glick, Weiss and Parkes (1974), Lindemann (1944), Parkes (1972), Parkes and Weiss (1983), and Raphael (1983). In reviewing the above work, one recognizes a general agreement concerning the existence of a final stage of grief: a point where one has come to terms with their loss and is able to carry on with life in a manner no longer profoundly affected by that loss. Parkes and Weiss (1983) believe recovery is characterized by getting used to rather than getting over the loss. Yet they maintain that if the process is going well, the major tasks will be accomplished in the first year while completion may take two to three additional years. Raphael, (1983, p. 47) stresses that "there is no fixed end point to mourning

during the first or even second year, but much of the work of relinquishing bonds is accomplished in the early months and continues gradually in steps and stages over the first year". Bowlby (1980) argues that expectations of the speed and completion of recovery following major loss are often unrealistic. Bowlby (1983, p. 101) maintains that for some, "pre-bereavement states of health and well-being may never be attained".

Most grief theorists agree that it is impossible to specify an exact point in time at which resolution should occur. However, it has been suggested that normal grief is resolved "more or less" within the first one to two years following loss. Certainly this time criteria has been widely accepted and applied in past and present grief research. This fact is disturbing for it is apparent that the notions of normalcy and resolution are subject to considerable conceptual variation and ambiguity. What aspects of "normal" grief lie beyond the first one to two years of bereavement and how do these residual elements change over time, if indeed they do change at all? These questions have yet to be answered. The issue becomes even more complex when one considers that prolonged grief or the continuation of normal grief responses beyond the first one to two years has frequently been cited as a distinguishing feature of unresolved grief, chronic grief and pathological grief (Lazare, 1979; Lindemann,, 1944; Parkes, 1972;

Raphael, 1983). The fact that these three terms are used interchangeably within the grief literature only adds to the confusion.

The conceptual variation surrounding resolution and the normal response to loss beyond the immediate bereavement period is quite apparent in the literature on perinatal bereavement. Some researchers have designated specific points in time for the resolution of normal grief. Corney and Horton (1974) assume that normal adult grief is of a short duration and normal mourning over the loss of an infant is resolved within a period of several weeks to several months. Rowe et al. (1978) studied perinatal bereavement and defined prolonged grief as symptoms evident at 12 to 20 months following loss. An example of morbid grief described by Rowe and co-workers included a mother keeping a picture of her stillborn infant on the mantle. Unfortunately, as with so many studies, these researchers made no attempt to delineate their criteria for resolved grief versus unresolved grief. Nor do they substantiate their conclusions regarding same.

Wolfe and associates (1970) studied grief and the mechanisms for its resolution in 40 mothers over a one to three year period following infant loss. Regrettably, the methodology failed to allow for the separate examination of parents at each time period. Rather, the one to three year interval was treated as a single follow-up time, thus

making interpretation of time or change over time virtually impossible.

Stack (1980) suggests that anniversary reactions and persistence of affect such as sadness and anger are indicative of unresolved grief, whereas others (Parkes, 1972; Raphael, 1983; Rando, 1984) consider these reactions to be natural and predictable following significant loss. Again, inconsistency in conceptualization makes interpretation of parent behavior difficult.

In a study of parental grief following loss through SIDS, Krein (1979) maintains that the average reaction to grief comes to a reasonable conclusion in six to twelve months, but may surface intermittently throughout the next several years. Kerner, et al. (1979) studied 16 families following the loss of a child from Cystic Fibrosis. These researchers found a "high incidence" of incomplete mourning in seven of the families. Criteria for incomplete mourning included a weekly grave visit for more than six months. These investigators were "surprised" that roughly one half of their sample was actively mourning beyond two years. Forrest et al. (1982) consider prolonged grief to be that which exists beyond 14 months post-loss. La Roche et al. (1982) maintain that extended follow-up is needed to better understand the evolution of grief. Nonetheless, these investigators studied perinatal grief reactions from the perspective that mourning may take up to 18-24 months.

Rando (1984) argues that follow-up research is often biased because it is usually limited to an 18-24 month period following loss. Without question, many follow-up studies conducted on bereaved parents over the past decade are subject to this form of bias (Benfield et al., 1978; Clyman et al., 1980; Johnson, 1984; Kerner et al., 1979; Krein, 1979; La Roche et al., 1984; Rowe et al., 1978; Videka-Sherman, 1982; Zahourek & Jensen, 1973). In some cases, the main purpose of the research was to learn about aspects of grief not directly related to resolution. Nonetheless, as Rando (1984, p. 115) concludes, the limitations of the time frame "precludes knowledge of what happens beyond that point in time". Furthermore, given the broad variation in definition and the widely accepted view that the resolution of grief is too complex to be limited to specific time and behaviors, it is difficult at best to draw conclusions from many of the studies which focus upon perinatal loss and resultant grief.

Investigators such as De Spelder and Strickland (1982), Rando (1984) and Zimmerman (1981) have developed broader, more flexible criteria for determining the resolution of grief. For example, Rando maintains that the concept of resolution is abstract and difficult to operationalize. She suggests that the progress towards resolution is far more important than the speed at which it occurs. De Spelder and Strickland (1982) maintain that

prolonged grief should be described in terms of its effects upon the survivor rather than in terms of duration. Zimmerman (1981) believes that resolution has been achieved when one realizes the pain will never go away completely. According to Zimmerman, healing comes when the individual begins to understand this fact. These ideas allow for a more extended process of a normal grief and for the notion that certain elements of grief are ongoing. Thus, what Wolfe and associates might define as prolonged, morbid grief, Rando and Zimmerman might interpret as a normal lingering aspect of grief.

Based on her research with bereaved parents, Rando (1980, 1983, 1984) stresses that some elements of the loss will always remain. She states that the total resolution of grief may never occur yet the bereaved will still have come to terms with their loss. Hagan-Arnold and Gemma (1983, p. 95) feel parents do not "get over" the death of a child, rather, they learn to live without; "the grieving process is long - life long." Peppers and Knapp (1980, p. 47) have studied the response of bereaved parents and have coined the term "shadow grief". These researchers believe that "for many mothers the satisfaction that comes from resolving grief never arrives". For many mothers, something undefinable remains and life is never the same again. However, Peppers and Knapp maintain that shadow grief is not debilitating, rather it is a covert, common

characteristic of the post-mourning response. Shadow grief is not considered a pathological variant of grief, and it may be preventable. Further research is needed to validate this theory. The notion that shadow grief exists, that there are unresolved, yet non-pathological remnants of grief has only been alluded to in the majority of grief literature and in the grief theory. Further investigation of this phenomenon is critical to our understanding the full dimensions of human grief. Perhaps it is shadow grief that sets human grief apart from that of other species.

CHAPTER III

METHODOLOGY

Design

The concepts of bereavement and grief have been studied at many levels of inquiry using a wide range of qualitative, quasi-experimental and experimental designs. The purpose of this study was to develop greater insight into the phenomenon of resolution and its meaning to bereaved parents. The specific questions posed in this study focused on aspects of the grief experience which had not been well described or understood in the literature. Therefore, the methodology best suited to the proposed study was a factor-searching design (Diers, 1979) which was descriptive, exploratory and formulative in nature.

Data Collection

Harris (1984) and Hutti (1984; 1986) argue for the use of qualitative techniques in grief research, particularly research at the exploratory level. Hutti (1986) emphasizes that a qualitative approach is critical if one is to understand specific phenomenon within the subject's context. Based on this rationale, and, given the particular focus of the research questions posed in this study, the research methodology was primarily qualitative in nature.

The simultaneous use of qualitative and quantitative techniques has been employed repeatedly and relatively

successfully in grief research, and in particular, research related to parental grief (Clyman et al., 1980; Forrest et al., 1982; Giles, 1970; Helmrath & Steinitz, 1978; Kennel et al., 1970; Kerner et al., 1974; La Roche et al., 1984; Rando, 1980; Rubin, 1981, 1982; Shandor-Miles, 1985; Videka-Sherman, 1982). Furthermore, the strength and value of this triangulation technique in research design has been described and supported by researchers such as Field and Morse (1985) and Glaser and Strauss (1967). Glaser and Strauss (1967, p. 18) argue that triangulation "allows for the collection of different forms of data on the same subject, which when compared will generate theory".

Both qualitative and quantitative techniques were employed in this study. Data were collected using a semi-structured interview guide (see Appendix A). In addition, the Texas Revised Inventory of Grief,(TRIG) developed by Faschingbauer (1981; 1984) was administered to each subject (see Appendix B).

Data collection took place in the subject's home. This provided a familiar, relaxed and private atmosphere for the subjects. In each case, every attempt was made to meet with subjects at a time that was convenient for them in order to minimize interruptions and distractions. Informed consent was obtained from each subject (see Appendix C). Thereafter, each individual was asked to

complete the TRIG. Following completion of the TRIG, the principal investigator interviewed the couple together, using a semi-structured interview guide.

Considerable debate exists within the research community as to what should constitute the smallest unit of measurement in a study such as this. Some would agree that the individual is the only valid unit, while others view the dyad, the family or a larger social system as appropriate units of measurement under the proper circumstances. In this study, given that both parents had experienced the mutual loss of their infant, interviews were conducted with the parental dyad rather than the individual parents themselves.

Clearly, the simultaneous interviewing of more than one subject presents a challenge to both the researcher and the subjects themselves. Stern (1986) studied aspects of family equilibrium with the addition of a new stepfather. Originally, 30 families were to be interviewed as a unit however, family resistance resulted in only eight, complete family interviews, with the remaining interviews involving five couples and eight individuals. One might view this occurrence as a serious methodological flaw in that the original intent was not realized. However, two points are critical. First, one must be clear about the focus of this particular study - the family. Regardless of the potential difficulty in

obtaining conjoined family interviews, one cannot study and fully understand a phenomenon which impacts upon a complex system without examining that system as a whole. One simply has no guarantee that the separation, measurement and reconstruction of the isolated sub-units of that system constitutes a valid or reliable assessment of the total unit.

Secondly, the data gathered from the eight families and five couples is valuable in and of itself and is not negated by the reluctance of other families to be interviewed together. Rather, this occurrence simply adds more information to the overall database. One may not obtain the ideal when conducting conjoined interviews; nonetheless, it is critical that the attempt be made when the issues at hand impact upon the system as a whole.

This holistic approach to the study of human experience is becoming more and more pervasive in the literature. Bernardo (1971) recommends the use of larger "kinship" groups as necessary and important units of study for social anthropologists. Swanson (1986) presents a compelling argument in support of using the couple as a "natural unit" of measurement in qualitative nursing research. Swanson emphasizes that nurses encounter, work with and care for "multiple units" in a variety of health care settings. It is therefore, both desireable and necessary for nurses to study multiple, natural units such

as the marital dyad or the family.

Swanson maintains that partners may be reluctant to disclose at times, in front of their mate. However, it is emphasized that joint inteviews may allow for the sharing of two different points of view, and the clarification of perceptions between partners. The author goes on to say:

> Perhaps the greatest advantage of interviewing multiple units is the rich data that may be obtained, giving range and variation to the categories needed for grounded theory development. (Swanson, 1986, p.72)

In the present study, parents were asked to jointly share their feelings and perceptions following the loss of their infant. Each parent was encouraged to respond to each of the questions posed by the interviewer. In addition, valuable data were gained from the verbal and non-verbal interactions which occurred between the parental dyad during these interviews.

The interviews ranged from one to three hours in length. Each interview was audio-taped which allowed for the precise recording of all the parent's comments.

Instruments

A semi-structured interview guide was developed from the literature on parental bereavement. The instrument consisted of open-ended questions designed to elicit parental beliefs regarding the events surrounding their infant's death, their present point in the grief process, their resolution of grief, the changing nature of their

grief experience over time and the lasting thoughts, perceptions and feelings experienced following the death of their infant. This method of data collection is phenomenological in origin and is designed to allow one to discover the "essence of meaning for the subject" (Field and Morse, 1985, p. 27). According to Diers (1979, p. 117) qualitative techniques such as this are essential if one is to collect rich, informative data and gain a broad perspective of the phenomenon under study.

The semi-structured interview technique has been employed effectively in numerous studies pertaining to parental grief. The technique has been utilized to study the extent of maternal and parental grief following neonatal loss (Benfield, et al., 1970; Giles , 1970; Kennel et al., 1970; LaRoche, et al., 1982, 1984), grief and adaptation following loss (Rando, 1980, 1982), parental guilt (Shandor-Miles, 1980; Johnson, 1984), the mechanisms of grief resolution (Wolfe, et al., 1970) and social support (Forrest, et al., 1982; Helmrath and Steinitz, 1978).

The TRIG is a self-rating scale developed by Faschingbauer (1981) to measure the extremity and nature of an individual's reaction to bereavement. The instrument has been used in a number of studies which have focused on the grief experience. Consisting of two scales, the TRIG provides a measure of the past life

disruption, present emotion of grief and progress through the stages of grief. The instrument has been shown to be a reasonably reliable and valid measure of the grief experience. The TRIG has demonstrated construct validity and has an Alpha co-efficient of .89 (split half = .82) for part II and .87 (split half = .79) for part I. Furthermore, the TRIG has been used to generate normative data for 422 bereaved individuals (Faschingbauer, 1981).

Description of the Sample

Based on the rationale provided by Diers (1979), Field and Morse (1985) and Glaser and Strauss (1967), theoretical or purposive sampling was used to select seven couples who had experienced neonatal loss, thus the total sample consisted of 14 individuals. Demographic data on each of the subjects is presented in Tables 1 and 2. The intent was to select nine couples who had experienced the loss of an infant in NICU. Three couples were to be chosen at each of the time periods under study: one, three and five years following the death of their infant. However, difficulties were encountered in recruiting subjects in the three year group. This will be discussed in greater detail below.

It was assumed that a sample of this size, although small, had the potential to represent the full spectrum of the phenomenon under study, as each of the subjects selected had specific characteristics and knowledge related to that phenomenon - parental grief (Field and Morse,

Table 1

Demographic Data - Parents

1-3 Yr. Group

Parent	Age	Education	1 Income	Months Post-loss	Other Children
Mr. A	31	Post-sec	> 50	11	M-1Yr.
Mrs. A	32	Post-sec			
Mr. B	31	Post-sec	50	13	Expecting
Mrs. B	32	Univ.			
Mr. C	27	Post-sec	20-50	21	F-1Yr.
Mrs. C	32	Post-sec			
Mr. D	28	Secondary	20-50	37	M-2Yr.
Mrs. D	26	Post-sec			

5 Yr. Group

Parent	Age	Education	1 Income	Months Post-loss	Other Children
Mr. G	38	Univ.	> 50	55	F-3Yr.
Mrs. G	41	Univ.			F-2Yr.
Mr. H	30	Univ.	20-50	65	M-2Yr.
Mrs. H	31	Post-sec			F-4Yr.
Mr. I	34	Secondary	20-50	64	M-3Yr.
Mrs. I	26	Secondary			Expecting

M - Male
F - Female
Post-sec - Post Secondary
Univ. - University
1 - Thousands of Dollars

Table 2

Demographic Data - Infants

1-3 Yr. Group

Infant	Life Span	Gestation	Cause of Death
M-A	7 wks.	31 wks.	Sepsis, Renal Failure Pulmonary Hemmorhage
F-B	36 hrs.	28 wks.	Hypoplastic lungs, Renal Agenesis, Potter's Syndrome
M-C	24 hrs.	32 wks.	Hypoplastic lungs, Renal Agenesis
F-D	4 days	40 wks.	Diaphragmatic Hernia, PFC., Hypoplastic lung

5 Yr. Group

Infant	Life Span	Gestation	Cause of Death
F-G	24 hrs.	42 wks.	Potter's Syndrome, Diaphragmatic Hernia
M-H	12 hrs.	34 wks.	Fulminating Sepsis,
M-I	5 hrs.	28 wks.	Respiratory Failure

M - Male
F - Female
PFC. - Persistent Fetal Circulation

1985). Often, sample size in qualitative research is limited in number. For example, Hutti (1986) selected a sample of two mothers in her exploratory study of the miscarriage experience. Harris (1984) included 13 subjects in her qualitative study on dysfunctional grieving related to childbearing loss.

According to Field and Morse (1985), it is not always possible to predict the required sample size. In the current study, a quota sample (Diers, 1979), of three families in each of the time periods under study was selected as a reasonable and manageable number of subjects to be considered.

In an attempt to minimize inherent differences in the sample, the following selection criteria were chosen. Couples were selected who: were of an Anglo-Canadian background, were able to read and write English, had no previous experience with perinatal loss, who were in a stable relationship at the time of the infant's admission to NICU and who resided in the Edmonton area. The initial contact was made by way of a letter of introduction (see Appendix D), followed by a telephone call (see Appendix E).

The sample was chosen from the medical records of a tertiary hospital with a large and active neonatal intensive care. Permission was obtained from the clinical investigation committee to review the charts of infants who had died in the NICU between January 1981 and June 1985.

According to the sampling protocol, subjects were contacted first by letter and then by telephone.

Six families whose infant died in 1981 were contacted before the desired number of three families could be recruited. Of the three families who did not participate in the study, one couple had divorced since the death of the child; thus, these parents no longer met the selection criteria. Of the remaining two couples, one wife decided not to inform her husband about the study feeling sure that he would refuse to discuss the situation with a stranger. In the third couple, the father did not wish to think about or talk about the loss at that point in time. In the latter two cases, both wives indicated they would have been willing to participate; however, this was not feasible as interviews were to be conducted with couples only.

Five couples whose infant had died in 1985 were contacted before the desired number of three families was obtained. Of the two couples that did not participate, one couple agreed that they did not want to "stir it all up again" at that time, but suggested they might be able to "help" at a later date. In the second couple, the father refused to participate and was adamant that his common-law spouse not be involved. Nonetheless, this mother offered to meet with the interviewer privately to participate in the study. Unfortunately, once again the selection criteria would not allow for the inclusion of this parent.

The most difficulty in finding and recruiting subjects occurred in the group who were three years post-loss. All charts of infants who died in 1983 were reviewed. In addition, charts from July 1982 through December 1982 and January 1984 through July 1984 were examined, thereby extending the boundary for the three year group to include parents who ranged from approximately two and one half to three and one half years following the loss of their infant. It was determined that extending the time frame for this group any further would lose any descrete differences or characteristics that might distinguish this group from the one and five year groups.

In total, 86 charts were reviewed of infants who died in NICU between July 1982 and July 1984. The search yielded 15 couples who met the selection criteria. From this group, nine couples could not be located or traced to another address, one couple had moved out of town and one couple was no longer together. Four couples were contacted and only one of those couples agreed to participate. Of the three couples who did not participate, one family was about to move out of province, one couple felt they would rather not "get into it" again and also questioned their ability to remember the events and feelings clearly after three years. In the remaining couple, the father declined to participate although the mother would have been willing to do so.

As noted previously, research in the normal grief experience over time has been limited and few studies have looked at the concept of resolution in a systematic fashion. This study extended the time period beyond the familiar 12-36 months and allowed for the systematic separation, comparison and analysis of the parental response and experience.

Data Analysis

Interview data were transcribed from the tape recordings and subjected to qualitative analysis to identify and describe the themes, concepts and ideas present. The subjective data for each individual were examined in order to determine the subject's perception of the meaning of resolution and the degree to which resolution had occurred for that individual. In addition, several concepts and categories were identified from the data which specified elements of the grief experience that remained ongoing and salient to parents beyond the point at which resolution had occurred. To ensure the validity of the conclusions drawn from the data, the concepts and categories were examined in conjunction with the data, by an expert in the area of bereavement. These concepts and categories were further developed and validated through a subsequent second interview conducted with a one year family and a five year family. Finally, the data from each group were analysed and compared in order to identify the

commonalities and differences which existed in relation to the parental perceptions of the resolution of grief.

In addition, each individual was assigned a score on the TRIG, indicating the degree or resolution evident. It was understood that the sampling method and size precluded statistical comparison of the TRIG scores. Nonetheless, the TRIG has demonstrated reliability and validity as a measure of the resolution of grief and standardized scores were available for comparison with the subjects in this study. Primarily, the TRIG scores were utilized as a means with which to substantiate, verify and evaluate the subjective data obtained from each participant.

Ethical Considerations

This research was subject to ethical review according to the guidelines set forth by the Faculty of Nursing, University of Alberta. In addition, ethical review and approval was obtained from the institution from which the study sample was drawn.

Spradley (1979) stresses that the rights, interests and sensitivities of the subject must be safe guarded. To this end, each subject was informed verbally and in writing of the purpose and nature of the study. The anonymity of each subject was assured and protected. All subjects were apprised of their right to withdraw from the study at any time and without penalty. Written, informed consent was obtained from each subject prior to his or her

participation in the study.

All interviews were conducted in a relaxed, sensitive and informal manner. Though clinical experience with bereaved parents supports the view that most individuals welcome an opportunity to discuss their loss, provision was made for parents to discontinue the interview if they wished to do so. None of the subjects requested that the interview be cut short. Furthermore, follow-up supportive counselling from the Director of the Pastoral Care Department in a large community hospital, was available had the parents identified such a need. Once again, none of the subjects expressed the desire to take advantage of this service.

CHAPTER IV

RESULTS

This chapter is comprised of three major sections. In the first two sections, the one and three year couples will be considered as a single group. The couples were grouped in this fashion as the three year group consisted of only one couple whose responses did not differ from those of the one year group with regard to the meaning of resolution and the degree of resolution achieved. The first section of this chapter includes a description of the degree to which parents in the one-three and five-year groups felt they had resolved their grief. The second section presents a description of the meaning attributed to the concept of resolution by the parents within each of the two groups.

Parental responses related to the last section of this chapter were not specific to any particular group, rather, they varied throughout the parent groups. Consequently, the third section will be reported according to the unique categories that fell within each group and not by specific parental groups. The third section will deal with the elements of loss and grief that are salient and ongoing in parents at the point of resolution and beyond.

Degree of Resolution

This section includes a discussion of the parents' comments concerning the degree of resolution achieved as

well as the parental scores obtained from the Texas Revised Inventory of Grief.

Parent Responses

Within both the one-three and five-year groups, parents identified the degree to which their grief had been resolved. All of the fourteen parents interviewed believed their grief had been resolved; however, in some aspects, parental responses differed within each group and between the two groups. Five-year parents were consistently less finite in their responses, each giving a "yes and no" answer to the resolution question. One-three-year parents varied more within the group, giving both a "yes" or "yes, but" type of answer. One-three-year parents were uncomfortable with a "yes, but" response while five year parents seemed quite satisfied with a "yes and no" response.

In both the one-three and five-year groups, mothers needed more time to reach a point of resolution than did their spouse. The findings described above will be discussed in detail within the following sections.

One-Three-Year Group. The majority of parents (6/8) in this group felt their grief had been resolved. The statement "yes, yet you never forget" exemplifies the responses commonly made by these parents. The remaining couple were less definite in their response. In this couple, the mother felt she had resolved her grief, yet

identified one area related to her loss that was not resolved:

> [Mrs.B] The hardest question I have to deal with now is when people ask if I have any children ... I find that tough ... I still haven't resolved it at times. What am I always going to answer? Maybe I will just answer differently.

In this particular couple, the father stated he was not sure about his degree of resolution. He indicated that he had "totally accepted" the loss. However, for this father, resolution did not mean the absence of feelings present during active grief:

> [Mr.B] I don't know, like we totally accept what happened and totally try to live life to the fullest every day ... that doesn't mean that you forget ... you probably have a lot of the same feelings but I think you are ready to live life again. It is a changed life and it will never be the same or as good as it was ... this is an experience that will always be with you.

In all cases fathers thought they had reached the point of resolution earlier or more quickly than did their spouse. Nonetheless, all parents indicated that they had come to this point gradually and that it was difficult to pinpoint any one event or time that marked the achievement of resolution:

> [Mrs.C] You know the pain is there and you keep dealing with it and you keep trying to see which is the best way to deal with it and how you can live with it - so you don't notice that you have changed and how you are dealing with the different situations ... but I think it is just too gradual to really pickup.

It seemed then, that the parents in the one-three year group felt their grief had definitely reached a point of resolution. Only one couple questioned their total

resolution of grief, allowing for particular aspects that still remained unresolved and for a sense that elements of the grief response continued to have an impact or effect even after the resolution of grief.

Five-Year Group. When asked to identify the degree to which their grief had been resolved, all parents in the five-year group (6/6) were less definite in their answer than were parents in the one-three-year group. All six of the respondents in this group indicated they had reached a form of resolution which was based on their personal definition of resolution. None of the five-year respondents were able to give an unqualified yes to the question of resolution. The comments of the five-year parents clearly reflected a sense that grief was both resolved and unresolved at the same time:

> [Mrs.H] You grow remote from it ... it changes in nature but it is still there.
>
> [Mr.H] You resolve the circumstance, you resolve yourself to the loss but I don't think you resolve grief. It is too intrinsic ... like trying to resolve breathing or thinking.
>
> [Mrs.I] Yes and no, because it always goes on.
>
> [Mrs.G] Yes as much as it could be.

Parents in the five-year group seemed to share the understanding that resolution was not an "all or nothing" phenomenon. There was also the notion among five-year couples that resolution occurred gradually over time. However, as indicated above, some elements of the grief

process and its resolution were still ongoing for this group. Five-year fathers, like one-three-year fathers seemed to reach the point of resolution more quickly than their spouse.

In summary, parental responses about the degree of resolution achieved, following the death of their infant were of two types. Parents answered with an unqualified yes, adding that "you do not forget" or parents gave a "yes and no" response, identifying that resolution can be present and yet not total. This latter response was consistently present in the five-year group, and was given by one of the couples in the one-three-year group.

Texas Revised Inventory of Grief Scores

The TRIG scores for each parent are presented in Table 3. According to the tested and hypothesized schema proposed by Faschingbauer (1981), all but three of the subjects in this study scored within the "abnormal" realm of potential grief responses.

Two of the five-year fathers were categorized as "usual resolved" and "usual unresolved grief", while one five-year father fell into the category of "morbid grief". An "absence of grief" was indicted by the score obtained by the three year father. Of the one year fathers, the scores indicated the following categories: "acute unresolved grief", "partially delayed grief", and "usual resolved grief".

Maternal TRIG scores for the one year group included: "prolonged grief" and "morbid grief". The three year mother's score was consistent with "absence of grief". This was also consistent with score obtained by her husband as noted above. In the five year group, grief scores revealed "morbid grief", "partially prolonged grief" and " prolonged grief".

It is interesting to note, that for the great majority of the parents in this study (11/14), the TRIG scores are not consistent with the personal perceptions of the degree of resolution achieved following loss.

Meaning of Resolution

Parents within both the one-three and five-year groups outlined the same general criteria to describe the meaning of resolution. These criteria included: acceptance of the loss, feeling good again, and getting on with life. Responses between the two groups differed in that five-year parents were able to describe, to a greater degree, several characteristics of the grief experience that remained even after grief had been resolved. These included: a sense of missing the infant, a sense that grief could be resolved and yet at the same time ongoing, and a notion that resolution was a fluctuating rather than a fixed state. Each of these points will be discussed within the following group specific sections.

Table 3

TRIG Scores

Maternal TRIG Scores

Parent	Part I-Past	Part II-Present	Grief Reaction Group
A	29(H)	45(H)	Prolonged
B	14(N)	39(H)	Morbid*
C	30(H)	48(H)	Prolonged
D	13(L)	29(L)	Absent
G	18(N)	42(H)	Morbid*
H	25(H)	33(N)	Partially prolonged*
I	38(H)	58(H)	Prolonged

Paternal TRIG Scores

Parent	Part I-Past	Part II-Present	Grief Reaction Group
A	20(H)	16(L)	Acute unresolved
B	8(L)	34(N)	Partially delayed*
C	16(N)	27(L)	Usual resolve*
D	13(L)	27(L)	Absent
G	17(N)	42(H)	Morbid*
H	15(N)	32(N)	Usual unresolved*
I	18(N)	30(L)	Usual resolve

H - High L - Low

N - Normal * - Hypothesized groupings

One-Three-Year Group

Generally, parents in this group defined the resolution of grief as a collection of states and activities that had been achieved. The essence of the meaning of grief did not appear to differ between men and women in this group. In resolving their grief, parents had reached a state of "acceptance", they were comfortable with the "occurrence, with themselves and with their feelings." To these parents, resolution meant they were able to "get on with life and live life to the fullest, not as though it didn't happen, but in spite of it."

Resolution marked a point where the pain had "lessened and become more bearable" and where one was no longer sad with each memory and thought of the lost baby; a point where good memories were associated with the baby as well as the thoughts of how sick the baby was during his short life.

The majority of parents (6/8) described their own meaning of resolution without question or qualification. However, the remaining two parents within this group did question their ability to clearly define resolution. In couple D, the father emphatically stated he was "over with it" (grief). Even so, he questioned whether anyone really knew what grieving and therefore what resolution was:

> [Mr.D] What do you call grieving? Just thinking about it every once in a while or laying down and bawling on the floor or hiding or what?

This father's statements indicated that one can have a strong sense of having resolved grief and loss and yet be unclear as to whether or not the resolution of grief has completely taken place. According to his comments, one's definition of resolution is dependent upon one's definition of grief. If merely thinking about the lost baby is viewed as a form of grieving, then thinking about the baby might also be viewed as an indicator that grief has not been resolved. The father in couple B provides a further example of this view:

> [Mr.B] I'm not sure about resolution ... we totally accept this and we are trying to live life to the fullest ... but you don't forget. Many of the feelings are still there but you are ready to get on with life again ... it is a changed life though, never the same or as good.

For some parents then, defining the meaning of resolution is complicated by the perception that resolving grief means more than achieving or not achieving certain states of mind or accomplishing certain tasks. There is a recognition that some elements of grief and loss remain even after one has accepted grief and gone on with life. Parents who held this view however, were not able to clearly describe the exact nature of these remaining elements.

Five-Year Group

According to the parents in this group, there seems to be a double edge to the meaning of resolution. Like the one-three-year group, five-year parents described similar

states and tasks which indicated the resolution of grief had occurred. Some examples included "accepting the loss" and "getting on with life".

In addition, parents in the five-year group identified several aspects of resolution that encompassed what some grief theorists might label unresolved or ongoing elements of grief. This then was the other "edge" to the meaning of resolution. Five-year parents consistently described not only what resolution was, but also what it was not, within their definition of resolved grief. Resolving grief did not imply that "everything was over and finished". Rather, some aspects of grief and grieving remained ongoing and might never finish, even after the parent perceived his or her grief to be resolved:

> [Mrs.H] You accept your grief, you accept your loss, but the missing is always there ... the missing becomes the grief.
>
> [Mr.G] At this point, I believe that it doesn't go 10, 9, 8, 7, 6, 5, 4, and so on. I will have to deal with this "5" as long as it goes on.

Five-year parents perceived the state of resolution as fluctuating. Even though parents had reached a point where they felt their grief had been resolved, there was a recognition that the degree or state of resolution would not always remain constant:

> [Mrs.H] I reach a point where I have accepted it and then something happens and I am bowled right over and I think maybe I haven't accepted it.
>
> [Mr.G] ... you keep dealing with it ... you deal with it when you see a child that brings strong memories of

what your little girl might have been and you get tears in your eyes.

The comments listed above exemplify a key point five-year parents raised in relation to the resolution of grief: the notion that resolving grief means not getting over, but rather learning to live with some aspects of the loss. This notion supported the belief expressed by parents that one could continue to deal with grief and perhaps continue to resolve some elements of the loss even though one considered his/her grief to be resolved. These elements will be discussed in more detail in the following section.

To summarize, in some respects, both the one-three-year and five-year groups shared a common perception of what it meant to resolve grief. Two fathers in the one-three-year group questioned their ability to make a firm decision about the meaning of resolution because of its discrepant nature. In contrast, five-year parents consistently offered and were apparently comfortable with a definition that integrated the notion that one's grief can be resolved and yet one can continue to experience certain elements of grief and loss.

Beyond Resolution: The Remnants of Grief

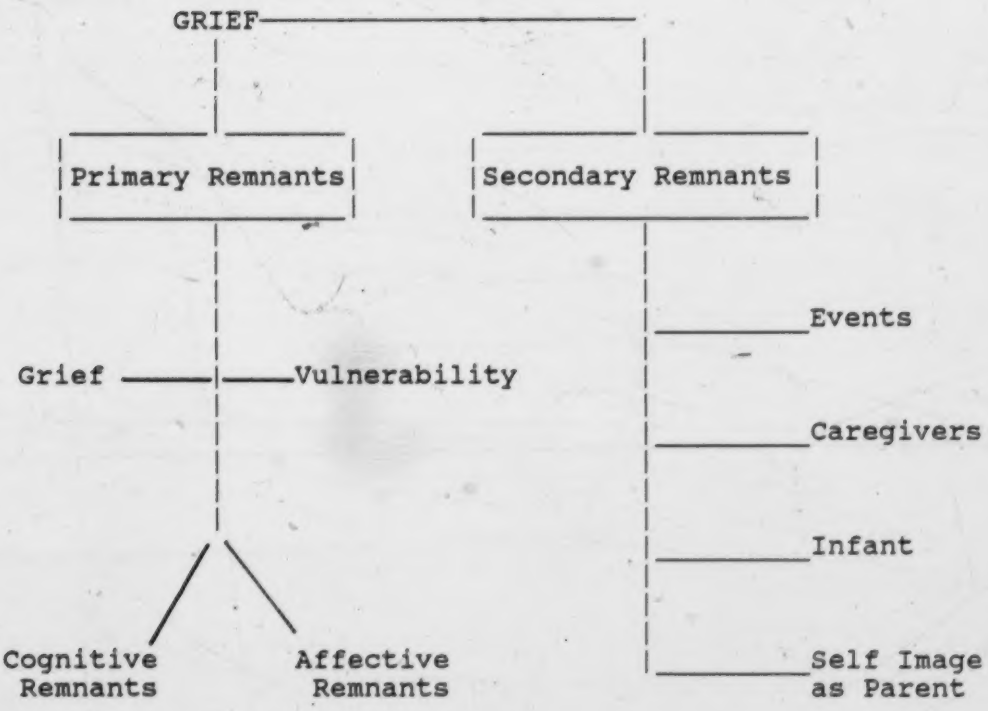
Several elements related to the experience of loss and grief, remained with parents to varying degrees, at the point of resolution and beyond. These elements are referred to as remnants rather than unresolved aspects of grief. Whereas the term unresolved implies "something" that has not

yet been finished, the term remnants clearly connotes "something" that is left behind or left over. The remnants identified by the parents in this study fell into two broad categories; those that were directly related or primary to the loss and grief experience, and those that were indirectly related or secondary to loss and grief. Primary remnants appeared to be a continuance of some direct aspect of the grief response, whereas secondary remnants appeared to be phenomena which occurred as a result of the total experience, however, they were not a direct part of it. For example, the remnants of "caregiver" and "parenthood" described below could exist in the absence of grief, yet their meaning in this particular circumstance is shaped by the grief experience.

Primary remnants fell into four categories: remnants of grief, vulnerability, cognitive remnants and affective remnants. Secondary remnants were the lasting impressions that centred around: the events that surrounded the loss, the caregivers encountered at the time of loss, the infant, and the individuals self image as a parent to the lost child. Each of these primary and secondary remnants are presented in the model below (see Figure 1), and will be discussed in the following sections.

Figure 1

Primary and Secondary Remnants of Grief



Primary Remnants

Parents in both time groups suggested that, beyond resolution, grief remained, but in an altered and more bearable form than existed prior to resolution occurring. Furthermore, parents identified certain cognitive and affective remnants associated with the loss and grief experience. Cognitive remnants included a sense of continued association with the lost infant, an increased awareness of the good experiences and relationships in one's life, and finding comfort in the meaning of the infant's death. Affective remnants included: feelings of love for the infant, pain, helplessness, anger, feelings of injustice, guilt and sadness. Several aspects of vulnerability were also identified as lasting remnants of grief. These included: a sense of diminished control over one's life, feelings of dread, and an increased sense of susceptibility to "re-experiencing" loss and grief. Each of these primary remnants of grief will be discussed separately in the following sections.

Residuals of Grief. Many parents believed certain aspects of the loss and grief experience continued, even though resolution was perceived to have occurred. Several parents suggested that the grief process or the response to loss continued but in an altered and less devastating form. The pain of loss and grief remained, but it was more "bearable". The nature of the grief experience had changed

over time, but grief remained:

> [Mrs.H] I think that one thing though is that the grief, as time goes by is not as intense. The intensity calms down and diminishes.
>
> [Mrs.B] ... you don't sort of feel the pain as much. You know, it sort of becomes bearable.

Some parents questioned whether or not one should expect grief to ever completely end. There was for these parents a belief that the grief experience would continue in certain ways and that this continuation was a natural phenomenon:

> [Mrs.H] Some form of grief is always going to be there ... almost everyone we talked to expressed a similar experience, older people have said 'you will always miss him. He will always be there. He was part of your life and you can't erase that'.
>
> [Mr.G] I am saying that I don't think it is bad, it is not a negative thing to have these feelings.

Cognitive Residuals. One of the cognitive residuals identified by several parents was a continued sense of the presence of the lost infant. For some parents, some of the feelings associated with grief and loss were welcome reminders of the lost infant:

> [Mrs.H] The better part of me is saying 'I'm not sure I want that' (being over and done with grief). I think I want to hang on to a part of him. ... I think it can be very healthy to keep those memories and to want to keep them and to share them.

Other cognitive residuals of the grief experience included the ability to appreciate to a greater degree, the relationships and experiences in one's life:

> [Mr.G] The up side is there too. I mean, look at the power of the feeling when the child is born and

everything is terrific. I mean the joy of the next two girls' birth is right at the other end. You never knew you had those kind of feelings in you to that degree.

[Mr.A] When I look at him next, I will probably think of Jonathan and I will think ... 'it is just so great now to have Bradley and he appears to be healthy.' That will be a really strong feeling I think.

[Mr.A] I am sure there is going to be a certain influence on your life, and different feelings. At work I deal with people all the time and I know this experience has changed some of the ways I perform my job now.

Parents described an awareness of personal growth and a sense of increased capability:

[Mrs.B] I feel like I am more prepared to be a parent now.

[Mrs.B] You are glad of the experience to make you a more understanding and compassionate person.

For a few parents, there was comfort in the lasting belief that the infant's death was probably for the best, or that the death had some meaning:

[Mr.A] I feel relieved in a sense that he did die under the circumstances because there were so many things that ... could have been so much trouble for him and for us too.

[Mrs.B] We sort of felt we could trust God. I also believe that she is in heaven and really happy there.

Vulnerability. Vulnerability was identified by many parents as a remnant of loss and grief. Vulnerability was experienced in several ways. Parents described the vulnerability that accompanied the realization that "this could happen to me". One father described a changed perception of his ability to control the outcomes in his life:

> [Mr.B] I think we look at it more as a gift now. For someone like myself who has always worked towards goals, you know, you work to buy this or to pay off this ... you always do that. All of a sudden, it doesn't work out like you planned and it makes you realize that 'hey it is not a right. It is a gift'.

In another sense, some parents identified a feeling of dread and vulnerability to a repeated experience of perinatal loss. These parents reported a feeling that they would not have the ability to go through the experience again:

> [Mrs.A] We were very happy when I got pregnant, but when I saw blood again I just went bananas and I was crying and I was even contemplating an abortion, which I knew I wouldn't have, but I was just trying to think about what I could do to get out of this because I couldn't go through that NICU bit again.

For some parents, there appeared to be a vulnerability to the "resurfacing" of, or "externalizing" of their remnants of grief. Even though parents believed it natural to continue to experience certain aspects of grief and loss, some parents reported a feeling of vulnerability in exposing their inner experience to others:

> [Mr.G] The only thing that you could say is if one could lessen it. Its just that you never know if there are incidents where you are not going to be able to hold on. Am I going to be out in public with her sometime and what is going to happen if we might see someone who strongly resembles her or has the same combination of names? This is our home ... but in terms of your public life, are you always going to be on top of it and control it? You never know what you are going to face.

Affective residuals. Parental responses indicated that they continued to live with and deal with feelings related to the grief experience even after resolution had

occurred. In some cases, the elements to be dealt with encompassed the whole experience:

> [Mrs.I] You just live with it and deal with it. It is not as intense or hurting or emotional, but it is there. I don't think a person ever loses that.

For other parents, the affective residuals were more specific. For example, one mother felt she would always carry a remnant of her sense of helplessness at the time of her infant's death. Anger was among the remnants for another parent:

> [Mrs.G] Yes, there is still anger. Anger that it had to happen. It is not directed to any particular part, it is just an anger that it could have happened and that we don't have this child which we should have. We experienced it and we should have something to show for it but we don't.

> [Mrs.I] ... you live with it, but I don't think, at least in my case, I don't think I would ever get over it. It will always hit me to the core. That was our child and there was not a thing I could do to help.

For a few parents, feelings of injustice and unfairness remained as affective residuals, even though acceptance of the loss and likewise resolution, had occurred:

> [Mrs.I] It wasn't fair ... there were a few instances where mothers abandoned their baby, or they would go in and have an abortion and I would think 'why are they allowed to get pregnant when I was not allowed to?' I felt that I was a better mother than they could ever be.

> [Mrs.G] We got jipped out of it. We experienced it and we should have something to show for it, but we don't.

Guilt was also identified by some parents as a remnant of their loss and grief:

> [Mrs.H] But I think I did take the blame for it ... I think I blamed me and that has been hard.
>
> [Mrs.I] I have always felt that I wish there would have been something else I could have done, maybe gone into the hospital sooner.

For many parents, one of the lasting affective remnants of grief was sadness. For one particular couple, the level of sadness had remained fairly constant. However, the perception and experiences related to this emotion varied:

> [Mr.G] So what I say when it changed from grief to sadness for me is that the sadness is mostly of the same kind now and probably a year ago and probably two years ago. I mean if I go to the grey side I get tears in my eyes but they only come to a certain point.
>
> [Mrs.G] Sometimes I think quite dispassionately about her. I can be very objective ... but then other times, for some reason, the emotion is very deep. Before I ... was always crying about it.

To summarize, lasting remnants, directly related to the experience of loss and grief remained for parents following the death of an infant in NICU. It is emphasized that all of the remnants were not reported by each parent. However, all of the primary remnants discussed above were evident to varying degrees throughout the parent groups. Parents in both the one-three and five-year groups described elements of the grief experience that persisted beyond the point of resolution as defined by the individual parent. These elements varied among parents as to their nature and intensity. Differences in responses did not appear to be related to the sex of the parent or the amount

of time elapsed since the death of the infant.

Secondary Remnants

Certain experiences and impressions accompanied or shadowed the loss and grief experience over time. Furthermore, comments made by parents indicated that these entities continued even after resolution was perceived to have occurred. These remaining experiences and impressions seemed to be closely linked to the experience of grief and loss yet, in many ways they seemed to be secondary to or apart from the primary process of grief.

The experiences and impressions reported seemed to fall into four groups: those which were closely related to the events experienced at the time of the infants death, those related to the people encountered at the time of the loss, those which seemed to relate to the notion of parenthood, and those that related to the infant. The following sections provide a description of the lasting impressions which fell into each category.

The Event. Parents recalled a sense of shock, urgency, a total lack of preparation and a strong sense of powerlessness when faced with the possibility that their infant might die. This reality, combined with the infant's obvious critical condition and the NICU environment, created for many parents what was described as a "nightmarish experience". Awareness moved between harsh reality and a dreamlike state:

> [Mrs.H] It sort of slaps you in the face as reality on one hand but on the other it is so foreign that it makes it a little dream-like.
>
> [Mr.H] The environment was kind of making your head spin because it was all so busy and crowded and rushed and bright. It is kind of like walking into an air traffic control tower in the middle of a crisis. Alarms are going off and this and that ... even then it didn't seem too bad until I saw Pat because he had IVs and respirators and stuff like that. It started to sink in at that point.

Some parents felt that time moved too quickly, that there was little time if any to prepare oneself for what was happening. This feeling was especially so when the baby died shortly after birth:

> [Mr.G] It was extremely brief ... when they took her away, then when the doctor came back to get the consent form signed he was really 'you've got to make your decision now. You don't have half an hour to think about this ... you sign this and your baby might live. If you don't sign this then your baby is going to die.' Period, that's the way he said it.
>
> [Mr.H] We were trying to grasp what happened. It was like trying to shake our heads and saying 'has this really happened, is this really true?'

When the infant survived for a period of time, there seemed to be a "slowing down" of the events. Parents felt they had more time to adjust to a greater degree to the realities of their situation. In addition, parents felt that they were more prepared for the actual death of their infant when it occurred:

> [Mrs.D] I wrote in my diary every day that she might die ... we talked about it a bit, even with relatives ... I just kind of accepted it.
>
> [Mrs.A] We were prepared. It was nice to have that week though. I kept wanting him to die because he was just so miserable. I was upset ... but in a way it was

> good to have that week to prepare or accept it, because I know the first three days of his life I was devastated.

Of the families interviewed, five couples were actually with their infant at the time of death. Some couples witnessed the last resuscitative efforts made to save their baby's life. Other parents were able to hold their infant in the last moments of life or just after death. Two couples did not have contact with their infant prior to, during, or after death due to the sudden and critical circumstances which accompanied the birth and death of the baby. In all cases however, parents maintained a lasting impression of the time and events which surrounded their infant's death regardless of the actual nature of the experience at the time.

The idea of time surfaced in another light in that some parents maintained a lasting impression of the amount of time they were able to spend with their baby. Understandably, this sensation was most strong in parents whose infant died shortly after birth. For these parents, there was a feeling that they had been "robbed" of time that was rightfully theirs:

> [Mrs.G] ... when I think about how quick they were to pick up this child who wasn't breathing properly ... sure I didn't get a chance to have her lie on my stomach but under some other circumstances maybe she would have lived and that would have been the deciding factor ... we don't resent that ... it is just resentment that it happened so quickly and we just didn't get a chance.

In summary, parents at one, three and five years following the loss of their infant all seemed to carry lasting impressions of the urgent, unexpected, and overwhelming nature of the events which surrounded the birth and death of their baby. It appears that several factors influenced the quality or impact of these impressions. These included the degree of perceived urgency and lack of preparation, the infants condition, the NICU environment and the length of time the infant survived.

The Caregiver. Within both the one-three-year and five-year groups, parents consistently and frequently referred to the caregivers as "They". This general term was used by all parents to describe the individuals who cared for their infant and the parents themselves. Thus, the term "They" was selected as a term of reference for the caregivers.

Data from both groups suggested a duality in the lasting impressions parents carried of the caregivers. Parental impressions of "They" centered around several aspects of the care given to both the infant and the parents themselves at the time of death and following the death of their baby. The duality of these lasting impressions was evident in that for each of the areas identified, parents were able to describe remnants that were both positive and negative in nature. For example, for the majority of parents, there seemed to be an impression of "They" as a

skilled, capable professional who was a source of comfort, care and support. In contrast, at the same time, many of these parents carried a lasting view of "They" which was associated with feelings of isolation, loneliness and abandonment. These "dual" impressions of "They" are described in greater detail below.

Initially, "They" were seen as the key to the infants survival. "They" were also the source of parental knowledge, understanding and support during the infant's acute illness. "They" were in control and parent responses reflected a feeling of real dependence upon the caregiver at that point in time. The majority of parents (12/14) perceived the caregivers as having the knowledge and skill necessary to save their infant and vividly recalled the actions and interventions undertaken as "They" provided care to the sick infant:

> [Mr.G] At the moment, all your faith is in the medical profession and if there would have been the opportunity for her to survive the operation and live then it would have happened.

In contrast, five years after the loss of their infant, one couple still questioned whether or not the caregivers acted quickly enough and in an appropriate manner. For this couple, there remained a lasting belief that their infant might have survived had "They" acted in a different fashion:

> [Mrs.I] They should have an obstetrician on call every shift because I wonder every day if he would have been okay. Could he have survived if I had carried him

another month ... its hard not to dwell on it sometimes.

There remained for many parents, both positive and negative impressions about the care given to their infants. Subtle aspects concerning the quality of care the infant received seemed to leave lasting impressions with parents. Remembering the tender loving care given to their baby created very positive lasting impressions:

[Mrs.A] They seemed very loving and they seemed to want to wind up his Teddy Bear.

[Mrs.D] ... they get attached to the little rascals too.

In contrast, some lasting impressions about the infant's care were remembered in a less positive light:

[Mr.A] That is not the fault of the nurses but that is one thing that I remember. Sometimes there seemed to be only one nurse to take care of six of them ... it bothered me that there wasn't as quick a response to alarms as I would like to have seen.

[Mrs.D] I never saw the night nurses ... it was during the night that she took all the dips and all the things that they don't like them to do. They had to bring her around all the time and that always happened at night. That really bothered me.

Many parents were left with a lasting impression of the control "They" exerted over the nature and extent of parent-infant interactions. In many cases, the acute and unstable condition of the infant and in some cases the mother herself, determined to a large degree the extent of the control exerted:

[Mrs.G] They whisked her away and we just waited. He came back right after the operation when we asked if we could see her ... do you remember that? [DG] Yes, he

> said 'no' ... because she was in intensive care and they are connecting all this stuff to her and it wasn't possible to get her out.

Again, the duality of this lasting impression was evident. Parents seemed to recognize and react to the control exercised by the caregiver, yet at the same time, there was an awareness that "They" were doing so with concern for the welfare of the infant:

> [Mrs.D] They said 'don't touch her so much, it takes too much out of her.' It seemed a bit unfair to me but then they explained that it was for her own good ... so of course I would do as they said.

> [Mrs.C] As soon as I saw him I knew he was mine and I wanted to just hold him close which I couldn't do ... They said 'there is your baby. You can touch his hands or his feet, but you cannot touch otherwise because he is tubed'.

In general, parental impressions of the caregiver also included a sense of being supported and cared for after the birth of their infant and at the time of death:

> [Mrs.C] The doctors were very good. They kept coming up and trying to comfort me and saying that there was nothing I could do ... They kept trying to inform me.

> [Mr.B] I don't think the nurses could have done anything different. They seemed to care and do everything that was needed. The staff sort of balanced the strangeness of the place. We really did find them compassionate and helpful.

> [Mrs.D] They were there all the time. When she was dying and I was going through that period, they were right by my side. I think that is what I needed. I probably broke that one nurse's fingers because I was clutching her hand so tight.

Dual impressions of care and comfort, as well as abandonment and isolation, appeared uniformly in parental recall of the experiences encountered after the death of the

infant. This phenomenon was described consistently by all parents, although the degree of discrepancy varied with each couple. Each couple was able to describe impressions of being comforted and cared for after the loss of their infant. For some parents, the lasting impressions were of the nurses who would come and simply spend time with them:

> [Mrs.C] She would come in the morning and say 'how are you doing' and I would start crying and looking out the window. She would come and sit and rub my back a bit and she said 'you will be okay...you go ahead and cry'. Then I would start to talk and she never said a word. She just let me talk...it was a good feeling that somebody made a special point...I think that is important.

A few Mothers in particular, recalled the gentle, physical care given to them after their loss:

> [Mrs.I] She came in to clean me up, I wasn't allowed to have baths or anything like that...she would come in and she was so gentle about everything...like an angel of mercy. I wish most nurses were like that. She was really something...I felt kind of bad that she wasn't always around.

Other lasting impressions included the guidance and reassurance provided by some physicians and nurses during the days that followed the infant's death:

> [Mrs.H] Dr. A was emphatic about...'don't blame yourself because it wasn't your fault...not something that you have done...you had no control over the situation.' It was nice hearing those things but it is not always that easy to stop doing it and believe it.

For some parents, lasting impressions of the caregivers included a belief that the caregiver had attempted to bend the rules or manipulate the system in order to protect and provide comfort in their time of

immediate shock and grief. This behavior included providing quiet, private times for spouse and family, bending visiting regulations and encouraging husband and wife contact:

> [Mrs.H] They were exceptional in some ways. I wanted 'J' to be there all the time with me. The nurse came in and 'J' was going to jump off the bed and she said 'oh stay there. Take off your shirt and get comfortable and just stay there. She needs you right now.'

At the same time, each couple carried lasting impressions which reflected a feeling of confusion at the avoidance and lack of care they experienced from some of the caregivers. For some couples, the care dimensions were overshadowed by impressions of isolation and loneliness:

> [Mrs.I] They were always there when you needed them ... as for the emotional part, I think ... they left me alone a lot because they didn't know how to deal with it ... as far as the physical needs and stuff ... they were pretty good.
>
> [Mrs.G] I felt that I wasn't, that they were somehow ignoring me because they didn't want to face up to the fact that I didn't have a baby and tried to be cheerful. [DG] Right ... the impression was that there may be one nurse that we warmed up to, who could deal with it. The rest were on an ... avoidance path because what do you do when you can't talk to the mother about her baby?

Some mothers carried lasting impressions of not receiving even the minimum of appropriate physical care following their loss:

> [Mrs.H] But the nurses were very interesting, they stayed right away from me ... didn't come in unless they had to. They didn't come in here and tell me what I needed to do to take care of my own body after delivery. Like the standard stuff ... that was something, I appreciated the privacy, but I was also frustrated because I had questions.

Lasting impressions for some parents also included a lack of sensitivity on the part of the caregiver after the death of the infant. Many parents were surprised and hurt by actions they perceived as thoughtless and uncaring:

> [Mr.D] Like there was this one nurse who came in and I usually don't get excited but if she had been a man I think I would have punched her ... she said she would like us to sign these papers about the baby 'expiring, I mean dying.' I don't think either of those words were proper for somebody three hours after their little girl died. I was very upset about that ... like 'get this paper work done so I can get out of here.'

> [Mrs.C] My doctor couldn't handle it which really upset my husband more than anything. He walked in the day the baby died and he asked me how I was. How do you say you are? Then he just patted my knee and said 'you will be fine.' Then he left and I never saw him again until I was ready to check out. A doctors job no matter how hard it is, is to help you.

It is interesting to note that most parents seemed to be able to provide a rationale which explained this discrepant phenomenon of caring and failing to care which was observed in the actions of "They":

> [Mrs.G] ... obviously nurses don't have time.

> [Mr.G] I'm sure nurses build up a certain invincibility to things because if you take everybody's troubles you might not be strong enough to deal with it.

To summarize, the majority of parents held lasting impressions of their dependence upon the knowledge and skills of the caregiver as they hoped for the survival of their infant. Clearly, the lasting impressions portrayed the caregiver as powerful and in control. In most cases, parents maintained a sense of having been cared for and

supported through the time that encompassed the birth and death of their infant. In addition, each couple retained a lasting impression of a discrepancy in the care and support received after the death of the baby. Unlike the perceptions of the powerful, caring, all-knowing "They" described above, some of the parental impressions of this time period portrayed caregivers who were insensitive, uncertain, and who were unable to face and deal with their grief and pain.

These discrepant impressions varied among parents as to their nature and degree of importance. This variance appeared to be related to the unique experience and situation of each couple rather than to the length of time elapsed since the death of the infant. For some parents, the lasting impressions were largely associated with the caregiver being present, understanding, providing physical care, information, reassurance and bending rules to allow for the needs of parents in the period immediately following loss. In other couples, the lasting impressions were more centered on the isolation, avoidance and the caregiver's lack of sensitivity to their feelings and needs, both physical and emotional.

Self-image as Parent. Each couple maintained a lasting impression of parenthood in relation to their infant. These impressions involved perceptions of parenthood at the time of loss and for some parents, a continuing sense of

"parenthood now" was evident. In addition, the notion of "hidden parenthood" surfaced as a lasting impression for parents in all groups along with lasting impressions of the interactions, memories and mementos associated with the lost infant.

Parenthood then

The majority of individuals interviewed (12/14) identified that they felt a sense of real parenthood at the time of their infant's birth. In general, mothers (6/7) were consistently more definitive than were fathers as to the degree of perceived parenthood. Statements from mothers tended to be more emphatic and included descriptions as to the nature and strength of their feelings for the baby:

> [Mrs.A] Yes I felt close to my baby ... like the first day, I was amazed at how strongly I was attached to him ... like the maternal instinct or whatever they call it ... I was amazed how strong I felt never having held him.
>
> [Mrs.H] I felt very close to him ... definitely felt like a parent toward him because I knew I loved him and I knew he was a part of me and I was very excited about having him.
>
> [Mrs.B] ... I was surprised at how much love I had for her ... an overwhelming sense of love. You kind of pinch yourself and say 'I am really her mother.'

Although less definitive, in their response, three of the fathers responded in a similar fashion to mothers:

> [Mr.C] I was very much his father, he was our son.
>
> [Mr.G] Absolutely ... she was our little girl.

[Mr.H] Yes ... maybe not as much in some ways as our present kids ... that is probably just a factor of familiarity ... so I wouldn't say quite to that extent but dead close.

Two fathers indicated that they felt like parents to their child; however, they sensed that their feelings of parenthood and attachment were not as strong as those of their spouse. These fathers seemed to need more time and contact with the infant in order to develop a sense of parenthood:

[Mr.A] Yes I did feel like a father ... I don't think I felt as strong or as close to him as 'B' seems to have been. Maybe the maternal instinct has something to do with it. I found myself even standoffish with him at times.

[Mr.I] It was about the same as 'B' I guess. I was never you know, when you're a man you don't have the same feelings.

Two fathers were less certain of their feelings of fatherhood:

[Mr.B] That is hard ... I don't know what to say. I guess it is always easier for the mother to feel close to the baby. After it is born the father can hold it and touch it and I think then you get more of a feel of it being a baby.

[Mr.D] No I did not feel close to her ... it was the first one so it was hard to accept to start with.

If the infant survived any length of time, it appeared that maternal contact was longer and different in nature than paternal contact. Mothers seemed to visit for longer periods and engaged in more touching behaviors than did fathers. This held true among the three groups of parents:

[Mrs.A] ... time passed very quickly... for me anyway. I just felt like, you know, I talked to him

> so he would know our voices ... read to him ... played his little wind up bear. After awhile, it made me feel good because ... they could never get his oxygen down ... but I was sitting there the whole time so I could keep turning his oxygen down.
>
> [Mr.A] I wasn't there for nearly as long as 'B'. She would be there for hours on end and I wouldn't. [MA] I think after half an hour he needed to get out. [DA] ... not as much time talking or reading to him. I did spend time talking to him and just letting him hold my finger. His hand wasn't even big enough to go around my finger.

Parenthood now

Impressions of "parenthood now" reflected an ongoing or continued sense of parenthood which was evident at the time of interview. There was no apparent pattern or association between the length of time the infant survived and the length of time that had elapsed since the time of death. Not all parents commented on their "parenthood now"; in general, however, those parents with a strong sense of parenthood during their infant's life exhibited that same sense of parenthood at the time of interview. Once again, mothers seemed to maintain a greater sense of attachment and relationship to the child than did fathers:

> [Mrs.H] He was really apart of me and a total individual to us and always will be ... no one will ever take that away from us.
>
> [Mrs.I] You include that part of your child's life with the children after ... it is always in the back of your mind and you can never forget. To me it would be totally cold and heartless if you did ... that was your flesh, your blood, your child.

One mother reported a sense of parenthood during her infant's life but recalled it was difficult to maintain

this feeling after the death of the baby due to a lack of validation of her parenthood from those around her:

> [Mrs.A] But then it wasn't until you went home that you didn't feel like a mother because nobody called or said that you had a baby or ... like I had been a mother but nobody treated you like you were.

Responses made by fathers demonstrated a variety of perceptions concerning "parenthood now". Some fathers did not experience the same feeling of continued relationship that was reflected in the maternal responses listed previously. Rather, "parenthood now" was perceived in terms of remembering or thinking about the baby:

> [Mr.A] I think about him a little bit and I go past the grave site on occasion ... but he is there.

For other fathers, a sense of continued parenthood was clearly evident:

> [Mr.B] Between us there is no question, we consider ourselves parents.

> [Mr.G] ... even at the length of time we did have her ... it is still deeply emotional, the ties are there.

Hidden parenthood

The notion of "hidden parenthood" arose for parents when those around them questioned the number of children they had had. Questions like "is this your first baby?" created a dilemma for parents as they recognized their real sense of parenthood to the lost child was not externally evident in a tangible way. Parents were then compelled to decide whether or not they would share the experience of their loss or simply give an answer which reflected the

"external reality" of their parenthood.

All parents reported an impression of "hidden parenthood" regardless of how long the baby survived or the length of time elapsed since the death of the infant. It was interesting to note however, that parental responses did seem to differ between mothers and fathers.

In general, mothers had greater difficulty in answering parenthood questions than fathers. Mothers consistently reported a greater sense of distress and guilt than fathers when their answer indicated the child had not existed:

> [Mrs.B] So the hardest question I have to deal with now is when people ask me if I have any children. What do you say? I had one, or just a simple no, or I don't know. When you say no it seems to diminish her, that you never had a little girl.

Responses from two mothers in the one year group indicated a reluctance to "deny" their infant at first, regardless of the circumstances that surrounded or led up to the parenthood question:

> [Mrs.C] They would say 'how old is your child'. I said, 'I had a little boy but he didn't live'. They don't know what to say ... you feel bad for telling them, but I think 'I had him and I'm not going to deny him'.

In contrast, all of the fathers (7/7) were able to provide a situational response to parenthood questions. Fathers would or would not identify their parenthood to the lost child, depending on the situational context of the question posed:

> [Mr.B] I guess it depends on how well you know the person and if they are just casually saying that (how

> many children do you have) like 'how is the weather', or if it is someone you know and are close to in some sense.

In most cases fathers seemed more comfortable with the situational approach to parenthood questions than did mothers. Although comfortable with this type of response, some fathers still reported feelings of distress when their answer denied parenthood to the lost child:

> [Mr.G] You make a decision every time. I mean people say 'how many kids do you have?' At that point, if it is going to provoke a discussion you don't want to get into you say 'no we have two' ... momentarily it hurts, even now.

Over time, mothers were more able to provide a situational response and with a greater degree of comfort:

> [Mrs.C] When people would say 'this is your firstborn' I would say 'no it is not'. Now I can live with saying 'yes we have one little girl'.
>
> [Mrs.D] ... I think of her but I say one.
>
> [Mrs.G] ... I find I do the same thing ... I vary my answer according to specific times.

To summarize, all parents maintained an impression of "hidden parenthood". In general parents experienced varying degrees of discomfort, distress and/or guilt when their answer denied the existence of a lost child. These feelings were reported most often by mothers in the one year group. On the whole, fathers seem to experience less distress associated with the phenomenon than mothers. In addition, fathers were able to develop situational responses soon after the death of their infant. For mothers, the ability to take a situational approach

developed over time. Mothers at three and five years post-loss consistently reported that they were able to make situational responses and were reasonably comfortable in doing so.

Impressions of the Infant. Parental responses suggested that a lasting impression of the infant was maintained through continued contact with the memories, mementos and emotions associated with the time shared with the infant, the death of the infant and the grief process itself. In general, many of the memories, keepsakes and emotions had both positive and negative connotations. Often these entities would be a welcome reminder of the infant, making the parent feel closer to the lost child. At the same time, due to the nature of the memory or memento, these reminders of the infant could also be a source of parental distress.

As with many of the lasting impressions related to the loss of the infant, the impressions of the infant seemed to be determined to a large degree by the unique situation and experience of the couple or parent. In some areas, the lasting impressions of the infant were also influenced to an extent by the length of time elapsed since the infant's death.

All parents interviewed retained lasting images of their infant in a physical sense and were able to recall specific characteristics that contributed to their lasting

impressions of the lost child:

> [Mr.A] I remember he would open his eyes, like when I would talk to him, I would get down close and talk to him, he would open his eyes. That was kind of neat.
>
> [Mrs.B] I think about tiny little fingers and toes and little hands ... her physical presence.

In other ways the lasting impressions of the infant's physical presence were less pleasant and more disturbing to parents:

> [Mr.C] There was never any indication that the baby was alive when I saw him. I realize that he had to be virtually paralyzed for his own sake, they had a lot of chest tubes in, but it was just a feeling that I could have been looking at a dead baby at the time.
>
> [Mrs.D] She had her surgery ... she had wires and tubes and was wired right up.

For some parents the lasting impressions included the feelings associated with their infant during his or her life. Parents repeatedly commented on the "pride" and " love" they felt for their baby. For other parents, even the feelings associated with the infant's death created lasting impressions of the infant himself:

> [Mr.G] I will never forget the image in the funeral home ... because that is the last time seeing her. It is just really that moment captured when whatever you felt at the time, like extreme sadness ... trigger memories and emotions now ...
>
> [Mrs.B] We were really proud of her too. When they first saw her, they really expected her to go at any moment and she continued to live ... she was really fighting hard.

Mementos and keepsakes served to create and maintain lasting impressions of the infant. These included pictures taken while the infant was alive and after death. Some

mothers kept poems and scrapbooks as reminders of their infant. One couple had video recordings of their infant during his stay in NICU. For a number of parents these keepsakes and the associated impressions were a positive experience:

> [Mrs.D] I have a constant reminder hanging in my bedroom. My Dad wrote a poem that night and it is just beautiful ... I look at it all the time and it is just beautiful.
>
> [Mrs.B] I look at her picture every once in a while ... that is really important. I am really glad for that because otherwise I would be afraid you would forget over time what she looked like.
>
> [Mrs.C] ... I hang on to my picture and my memory of holding him.

For other couples, there were no tangible reminders of their infant's existence. Or, in some cases, the only real evidence of their infant's life was the autopsy report or pictures which brought back unpleasant images. In these cases, the lasting impressions of the infant were more difficult to assimilate and hold on to:

> [Mrs.B] Sometimes I almost feel bad because there is nothing in our house to suggest to someone that we have had a baby.
>
> [Mrs.H] I am thankful that you (husband) had a chance to hold him in the caseroom when we thought he was totally healthy and normal ... in terms of the tangibles that is all there was other than the pictures and the autopsy reports and those are quite negative things.

Even though many of the reminders and mementos of the lost infant were perceived as difficult or painful, parents responses indicated a reluctance to give them up. These

reminders were part of the infant and as such were important to parents:

> [Mrs.H] They are not really positive ... but there are times now when I go 'I want those, I want to look at them, I want to go through them'. Not as a reminder of the grief ... but it was his.

All parents had periodic thoughts about their infant, often triggered by an anniversary date or some other reminder of their loss. Some parents were able to maintain lasting impressions of the infant not only by recalling the events that occurred at the time of birth but also by fantasizing what might have been if the infant had survived. It was interesting to note that these impressions often seemed to create feelings of closeness and loss at the same time:

> [Mrs.I] I think about him, like I said what he would look like and even things that he might be doing at that particular stage or seeing him with birthday cake all over his face. It's tough though.

> [Mr.G] ... you see a child that brings strong memories of what your little girl could have been and you get tears in your eyes.

Lasting impressions of the infant were also associated with parental recollections of the holding experience. The parent's experiences with holding their infant varied considerably. Some parents held their infant while the baby was alive, others held at the time of death. Some parents only held their infant after death, while a few parents did not hold the infant at all.

All mothers reported strong feelings associated with holding their infant. Maternal responses indicated there was a great need to hold their infant:

> [Mrs.H] Very enjoyable (holding). I wanted it very badly. I wanted to hold him and I didn't want to give him up, I remember that ... it felt like I was holding him forever.

> [Mrs.D] It was a real release, I think for me. If I hadn't gotten to hold her I don't think it would have been so easy for me to let go.

Three mothers were able to hold their baby while he or she was alive. For these parents, the lasting impressions of having held their infant were very positive, and comforting:

> [Mrs.B] I also got to hold her, that was good. It sort of brings it home to you because it is your baby.

> [Mrs.A] It was good (holding). I just wish I could have held him longer ... if I ever had it to do again, like I never held him until I knew he was dying ... I didn't want to disturb anything that would make his oxygen go up. But I think if I had to do it again ...

Three mothers held their infant at the time of death or after death had occurred. Once again, responses indicated that this experience left positive and comforting lasting impressions:

> [Mrs.C] It was like ... I felt good that I had my time as I did.

> [Mrs.H] I would have gladly held him for an hour of or two hours if they would have let me.

Each of these mothers indicated she would like to have held her infant while he or she was living, but was unable to do so because of the baby's condition:

> [Mrs.C] As soon as I saw him I knew he was mine and I wanted just to hold him close which I couldn't do.
>
> [Mrs.D] Touching was better than nothing, but I wanted to hold her really bad. I can remember feeling that every time I went up there, if I could just pick her up, even with the wires, but I couldn't of course.

One couple was unable to hold their infant at all due to the critical condition of the infant at birth and because the opportunity to hold was not provided after the baby died. For these parents, the lasting impressions related to holding were painful:

> [Mrs.G] I do know that I regret not having held her. She didn't know that we loved her, you know. That is hard even now.
>
> [Mr.G] The need to have held and touched and carried is a very strong emotion.

Two fathers did not hold the infant because they did not want to interfere with the time their wives had with the baby. In retrospect, both fathers indicated they would hold their infant if given the opportunity again. One father held his infant, but indicated he did so for his wife's sake, rather than from a desire to do so for himself. Two fathers preferred not to hold their infant at the time of death. Of these two, one father felt some regret at not having held his infant while the other did not. One father who did hold his baby after death was left with mixed feelings about the experience:

> [Mr.C] I felt kind of cheated that I wasn't actually holding him to take him home. We were holding him after he had died which was unfair.

Finally, some parents maintained lasting impressions associated with giving the baby up after holding. For these parents there remained a sense that they had not been given enough time with their infant:

> [Mrs.C] I remember the nurse came back and I told her I wasn't ready. She left again and when she came back the next time she brought the doctor ... the first time I would have been hurt because I wasn't ready ...

> [Mrs.H] I felt like I should give him back. I had the feeling that I was expected to give him back and I didn't want to ... it was like part of me was being taken away before I was ready to give it up. I wanted to share those moments with 'J' a lot longer.

The experience of holding their infant created a variety of lasting impressions for some parents. Impressions of holding the infant during life seemed to differ in nature from the impressions of holding during death or after death. Yet, for most parents holding the infant at any time was associated with positive and comforting impressions of the infant. At the same time, for some parents, impressions of holding were connected with sadness and regret. In general, it seemed that impressions of holding were described as stronger and more significant by mothers than fathers.

CHAPTER V

DISCUSSION OF RESULTS AND IMPLICATIONS

The purpose of this study was to examine the nature and duration of grief experienced by parents over time, following the loss of an infant in NICU. In particular, the intent was to explore the meaning parents attributed to the phenomenon of resolution and to identify the elements of loss and grief that remained with parents at the point of resolution and beyond.

All of the parents in this study indicated that their grief had reached a point of resolution, although the exact definition and meaning of resolution varied between the parent groups. As time passed, parents came to understand, to a greater degree, that resolution was not an all or none phenomenon, but rather an ongoing and dynamic state.

Several lingering elements of the grief experience were identified by parents within the three groups. These remnants fell into two general categories; those that were primary to the grief experience and those that were secondary to the grief experience.

This chapter is comprised of five sections, the first of which presents a discussion of resolution as an enduring phenomenon in parental grief. In section two, a new model for the resolution of grief will be considered and compared to the theoretical model currently held by grief theorists. Section three will present the implications of the findings

of this study for the practice of nursing and for further research in the area of parental grief. In the final sections of this chapter, the strengths and limitations of this work will be considered, along with a brief summary.

Resolution: An Enduring Phenomenon

Within this section, the parents' perceptions of the meaning of resolution will be considered along with a discussion of the current theoretical view of the resolution of grief. In addition, the lasting remnants of loss and grief identified in this study will be reviewed and their relevance to the current understanding of parental grief will be examined.

Resolution: The Parents' View

The most significant finding of this study was that the meaning and the experience of resolution differed, in subtle ways, between the one-three-year and the five-year groups. Irrespective of this difference in meaning, virtually all of the parents in the study felt they had resolved their grief based on their own definition of resolution. Furthermore, the criteria that parents used to define resolution was consistent throughout the parent groups. These criteria included "getting back into a normal routine", "feeling good again", and "enjoying life". This definition of resolution was in agreement with the that held by a number of grief theorists. According to Bowlby (1980) and Parkes and Weiss (1983), resolution is characterized by "re-organization".

Raphael (1983) believes individuals have resolved their grief when they have achieved a satisfactory adjustment to the loss and have been able to "re-integrate" themselves into life again.

However, five-year parents projected, to a greater degree, a sense that resolution meant to some extent, "learning to live" with loss rather than "getting over loss." This finding is consistant with the belief of Parkes and Weiss (1983), who contend that recovery is characterized by "getting used to" rather than "getting over" loss. In addition, at five years, parents were consistantly able to project not only what resolution was, but also what it was not, whereas parents in the one-three-year group were less clear on exactly what was and was not left behind. Parents in the five-year group were able to acknowledge and identify several aspects of the grief experience that remained, even after the parent had resolved his or her grief. Furthermore, parents in this particular group were better able to accept and feel comfortable with this unique characteristic of resolution.

It seemed that, over time, the state of resolution was less clear cut or finite, and yet at the same time, parents seemed to feel more comfortable with their state of resolution. It may be possible then, that the meaning and experience of resolution change with the passing of time. Parents at one year may be resolved to their loss, but their

resolution is of a different kind than that of parents who are five years post loss or even beyond. Brice (1982) has suggested that the process of grief is a moveable and developmental phenomenon. Likewise, Parkes (1972) has referred to grief as a dynamic state. If the total process of grief can be conceptualized in such a fashion, it is not unreasonable to conclude that resolution, as a component of that process, could be equally dynamic and moveable. It may be that the current theoretical perception of resolution is most reflective of the early stages of that state. That is to say, what is currently believed about resolution seems to be more in line with what the one-three-year group describe as opposed to the perceptions of the five-year group.

Traditionally, grief theory has not allowed for this developmental view of the phenomenon of resolution. Indeed much of the grief theory presents a dichotomy for the state of resolution; grief is either resolved or unresolved. Often, unresolved elements of grief are considered as abnormal and potential blocks to the healthy resolution of grief (Lazare, 1979; Lindemann, 1944; Parkes, 1972; Raphael, 1983). Furthermore, although theorists present different definitions for the concept of resolution, within a given theory, the concept of resolution itself does not vary (Bowlby, 1980; Parkes,1972; Parkes & Weiss, 1983; Raphael, 1983). The parental perceptions of grief and its resolution presented in this study are thought provoking,

and compel one to question whether or not the concept of resolution needs further consideration and development.

Resolution: A Theoretical View

Within the grief literature, resolution has received general acceptance as the "end point" of the grief process. The discussion of grief and its resolution presented in Chapter Two, clearly illustrated that this view is a fairly consistent theme throughout the majority of grief research. According to popular theory, as time passes, resolution will occur in the normal grief response and at the point of resolution, the major tasks of grief have been accomplished and the ongoing elements of grief have been settled.

Several grief theorists have presented the idea that certain aspects of the grief response may persist, even though the bereaved individual has come to terms with or resolved his/her loss. For example, Bowlby (1981, pg. 101) suggests that an "occasional recurrance of active grief ... is the rule", especially in the face of a specific reminder of the loss. The data from the present study indicate that parents continued to periodically experience certain aspects of grief, as a remnant of their loss experience, even after grief had been resolved. Furthermore, the recurrance of a sense of loss and grief was induced and/or heightened for several parents by reminders of the lost infant. From the data, it appears that, this "re-experiencing" phenomenon diminished in frequency and

intensity over time.

Rando (1983; 1984) has proposed that total resolution of grief may never occur and yet, the bereaved parent will have come to terms with loss. Once again, the data from this study are consistant with Rando's theory. In describing the meaning of resolution, parents at one, three and five years post-loss indicated that they had resolved their loss, yet, certain elements remained. These elements will be discussed in greater detail below. At this point, it is important to note that parents identified these lasting elements within a normative definition of resolution, and that over time, parents were better able to understand and distinguish between those aspects of grief that were resolved and those that remained.

Hagan-Arnold and Gemma (1983) contend that, after the loss of a child, grief remains forever, along with the memories associated with the lost child and the vulnerability which arises after experiencing loss. The view of these authors, based on their clinical observations, is supported by the findings of this study in that grief, vulnerability and lasting impressions of the infant were among the enduring remnants for parents who had suffered the loss of an infant in NICU.

Many of the current grief theorists, such as those cited above, recognize the existance of ongoing elements of grief. However, most theories of grief do not develop or

expand on this concept as it pertains to the notion of resolution. Nor does current thinking seem to conceptualize the enduring elements of the grief experience within a normative framework of grief. Most often, residual elements of grief are an "add on" at the end of theoretical discussions of the grief process. As such, these remnants take the form of ambiguous or ill-defined leftovers, that do not provide direction for a clear understanding of what indeed is left behind or how that might impact on the total grief experience.

Based on the findings of this study, there is some evidence to suggest that the phenomenon of resolution is more complex and more dynamic in nature than previously believed. It is clear from the results of this study, that the concepts of resolution and remnants must be considered together if one is to fully understand resolution as an enduring and evolving phenomenon in the grief response. From the results of this study, it was evident that the remnants of grief help define the shape and meaning of resolution for the individual; that is to say what resolution is and is not. Furthermore, based on the findings of this study, it is postulated that the remnants of grief are in fact what grief becomes once resolution has been achieved. The concepts are therefore, indisputably linked. In that the intensity and experience of these remnants seem to change over a period of time, so then does

the experience and meaning of resolution.

Several residual elements of grief were identified and categorized (see Figure 1, pg 91), in order to provide a degree of conceptual structure to those nebulous, remaining elements of grief, so often alluded to, but rarely, if ever defined and described within the grief literature. This lack of conceptual concreteness is exemplified in the work of Peppers and Knapp (1980, pg. 47-49) who coined the term "shadow grief", to describe the lasting sequelae of loss and grief. Having studied parental loss, for a number of years, these authors suggest that shadow grief is the "something" that remains after loss has occurred. According to these authors, "shadow grief" is a common characteristic of the post-mourning response. Shadow grief is described as a "ache" and an "emotional dullness" which is frequently accompanied by tears and always accompanied by sadness. Peppers and Knapp believe that shadow grief is partly the result of bottled up grief that remains unresolved and "seeps out in shadow form years later". It may be however, that shadow grief is the result of normal remnants of loss and grief, rather than unresolved grief.

Based on their work with bereaved mothers, Peppers and Knapp also believe that the phenomenon of shadow grief may be the result of a parent's, need to maintain a continued sense of their lost child. This belief is supported by the data obtained in the current study. Both mothers and

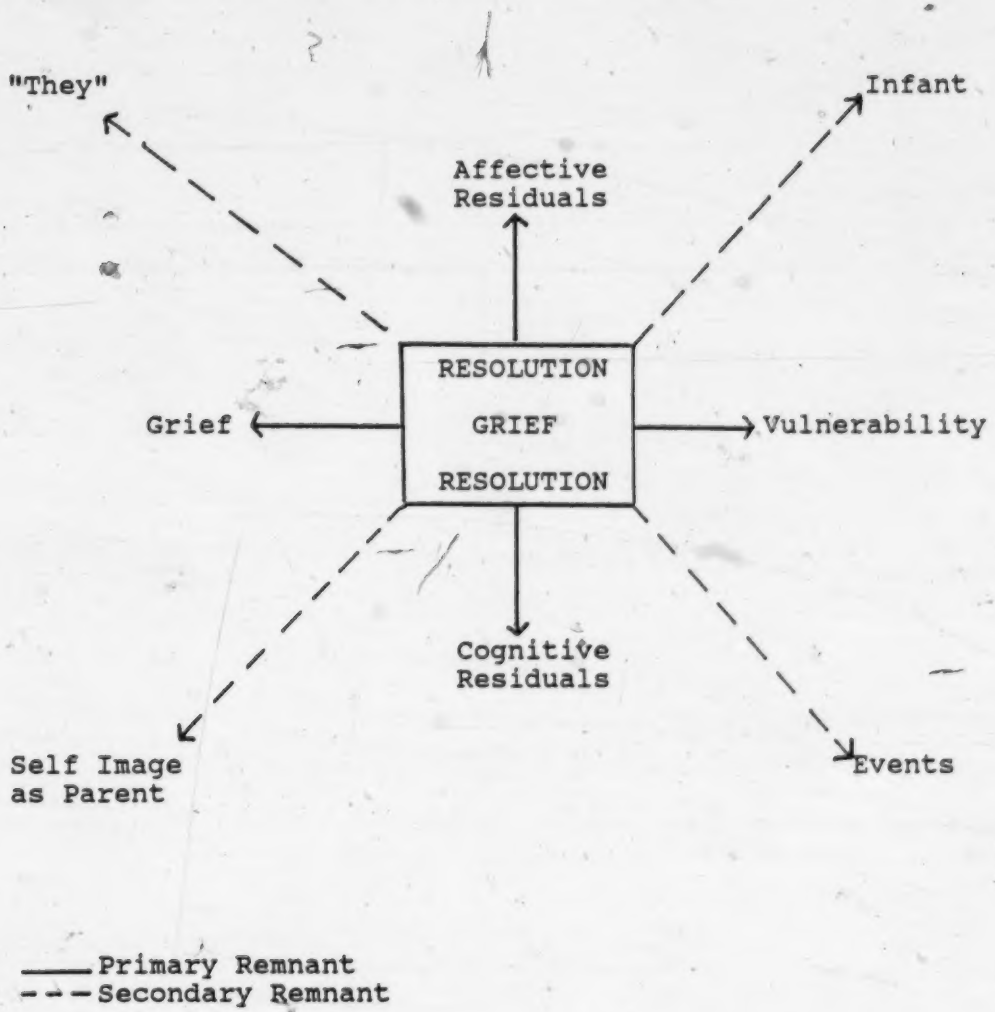
fathers indicated that sensations of grief had the potential to be positive remnants in that they produced feelings of closeness to the lost infant.

While Peppers and Knapp are to be commended on their sensitivity to this lasting phenomenon of grief, their definition of shadow grief is vague and difficult to incorporate in a meaningful way, into a broader understanding of the grief process. It is possible that the conceptual development of shadow grief could be expanded to include not only the unresolved aspects of grief which resurface, but also the lasting remnants of grief which remain, even after resolution has occurred. This would be particularily appropriate in light of Peppers and Knapp's contention that shadow grief is a common, non-debilitating characteristic of parental grief. Once again, the findings of this study provide evidence that a theoretical schema such as this is possible. The model depicting the lasting remnants of grief presented in Figure 2 serves as an example of how this schema might be developed.

Unfortunately, more often than not, lasting elements of grief such as those identified in this study, are considered to be unresolved and therefore abnormal sequelae of grief. Herein lies the difficulty that arises when one looks at resolution as an all or none phenomenon. As mentioned above, parents experienced grief itself, as a remnant of loss and grief. While authors such as Bowlby (1981), Rando

Figure 2

A Model for Primary and Secondary Remnants



(1983; 1984) and Hagan-Arnold and Gemma (1983) consider this to be a "normal" phenomenon of grief, other researchers have identified the continuance of grief as an indicator of abnormal grief.

In their study of grief following spontaneous abortion, Corney and Horton (1974) considered chronicity of normal grief to be one of the indicators of pathological grief. The authors did not however, set clear limits for what constituted chronicity. In the present study, parents at one, three, and five years following the death of their infant admitted to continued, periodic episodes of grief, and considered this to be expected and normal. This belief appeared to strengthen over time. Nonetheless, by the criteria set by Corney and Horton, the parents in this study would be suspect for abnormal grief.

Stack (1980) maintains that: persistence of affect when discussing the loss, crystal clear memories of the events surrounding loss and frequent flashbacks are related to unresolved grief. Likewise, Lazare (1979) believes that unresolved grief is evident if the bereaved is unable to to discuss the deceased without crying, especially after more than a year has passed. In a study conducted by Rowe et al (1978), keeping a picture of a stillborn infant on the mantle was identified as an abnormal behavior and associated with an pathologic grief response.

In the current study, vivid, lasting impressions of the caregiver and the events surrounding loss were described by parents within each group. In addition, the majority of the parents interviewed continued to experience a "persistence of affect" when discussing their infant. For several parents, mementos such as a picture of their dead infant or an autopsy report were the only tangible reminders of the lost infant. The criteria of Stack, Lazare, and Rowe and his associates, would indicate unresolved or potentially unresolved grief if applied to the parents in this particular study. However, the parents themselves believed they had come to terms with their loss. Rather than symptoms of abnormal grief, parents viewed behaviors such as continued affect, or vivid recall of events, or cherishing autopsy reports as expected and natural remnants of grief.

Current grief theory lacks a clear conceptual framework for resolution as a process and for the enduring elements of grief that remain within a normative context after resolution has occurred. Likewise, the measurement of resolution of grief is generally not sensitive to the notion that resolution, like grief, may alter over a period of time, or that certain lasting remnants of grief are part of the normal grief response. For example, the Texas Revised Inventory of Grief, utilized in this study, is designed to measure the extremity and nature of the grief reaction, with a view to identifying those individuals who

are experiencing complicated or prolonged grief. The outcome of this measurement is a score which depicts the individual's state of resolution. The test does not however, allow for the possibility that resolution itself may follow a natural process of evolution.

In the current study, comparing the parents' own perception of their degree of resolution to individual TRIG scores yielded several discrepancies. First, even though all of the parents felt their grief had been resolved, the TRIG scores were highly consistent with complicated grief responses, in all but three cases (see Table 3 pg.43). Exactly half these abnormal grief responses fell within hypothetical categories which have yet to be fully tested. Nonetheless, many of the parental views conflicted with their TRIG scores. This suggests that, either the parents are not sensitive to their own state of resolution, or the TRIG has in some way failed to distinguish between the normal and abnormal lasting elements of the grief response. Instead, all of the remaining elements have been recognized as abnormal or unresolved aspects of grief.

Faschingbauer (1981) does hypothesize a category of "usual unresolved" grief. However he does not expand on the exact nature or characteristics of that category. Once again, one is left with a vague and ill-defined understanding of what the usual, lasting remnants of grief might be, or indeed, how these remnants might fit into the

broader understanding of grief. The data from this study have been used to generate a schema for the lasting elements of grief which might be useful in further defining the concept of resolution within contemporary grief theories.

Additionally, this schema, allows for the existence of enduring aspects or sequelae of loss and grief within a normative context. Thus, what the TRIG depicts as unusual or abnormal factors might be further broken down into resolved grief with usual primary and/or secondary remnants. Perhaps, with categories such as these, the TRIG scores would have been more consistent with the parents' subjective assessment of their state of resolution. Finally, the model for the lasting elements of grief presents a method of identifying and categorizing the "undefinable things" described by researchers such as Parkes and Weiss (1983), Rando, (1980, 1983, 1984), and Pepper and Knapps, (1980).

Based on the above observations, there is still a high degree of confusion surrounding what constitutes the abnormal versus the normal sequelae of grief: what they are, how they are experienced and how long they may be expected to last. The findings of this study, provide support for a conceptual model for grief which would include a pathway for the normal, as well as the abnormal lasting elements of grief. Such a model would allow for the presence of lasting remnants of grief within a framework of normal, resolved grief. At the same time, the model would enable one to

determine to a greater degree than is currently possible, what the real differences are between the cognitive, affective and behavioral characteristics common to resolved and unresolved grief.

Remnants: Towards an Understanding

As mentioned in the previous section, a limited amount of theoretical structure exists in relation to the normal, lasting remnants of grief. And, as the discussion in Chapter Two revealed, much of the current thinking concerning the resolved and unresolved elements of grief, and their impact upon the outcome of grief, is ambiguous and difficult to interpret in a meaningful way. Within this section, each of the lasting remnants of grief identified in this study will be discussed in relation to their significance to the understanding of the grief process and its outcome. Primary remnants will be considered first, followed by a discussion of the secondary remnants.

Primary Remnants. Within the following section, the primary remnants of grief will be considered separately in order to examine the unique qualities of each of these enduring elements of grief.

Grief

The fact that grief may continue for some time after significant loss has occurred, has been recognized by many grief researchers (Bowlby, 1982; Parkes, 1972; Parkes & Weiss, 1983; Rapael, 1983). In some of the more current

work in grief research, particularly that done in the area of parent grief, there is a growing belief that parental grief may be prolonged and difficult. For example, Miles and Perry (1985) contend that the loss of a child constitutes one of the most stressful life events one can endure. Rando (1984, pg.129) suggests that parents "grow up with the loss, in a grieving process spanning years". Segal, Fletcher and Meekison (1986) studied 68 bereaved families to determine their perceptions and experience of loss. According to these researchers, the death of an infant may have devastating effects on parents and the family as a whole. Hagan-Arnold and Gemma (1983) maintain that the longing and emptiness a parents feels following loss may last a lifetime. These authors believe that a parent grieves forever when a child dies. They also suggest that the normal grief response of parents would fit the picture of pathological grief held by many grief theorists.

Based on her study of the maternal grief experience following the loss of an older child, Edelstein (1984, pg.17) believes "for bereaved mothers, full investment in life and its activities is a hard-won battle, happening slowly and filled with setbacks". Unfortunately, Edelstein, like so many others, recognizes this ongoing nature of grief, but does not demonstrate that recognition in her theoretical conceptualization of grief. Edelstein (1984,pg. 18) writes, "resolution or reorganization although the

optimal outcome, is not the only possible resolution in bereavement. There are also a variety of possible deviations to the process." The author is suggesting on the one hand that grief may be prolonged in the normal grief response of bereaved parents, and at the same time, her conceptual framework seems to allow for only two possibilities: reorganization or deviation. There is no provision for grief to endure as a normal component within this framework. Edelstein does not incorporate the lasting elements of grief into her discussion of "reorganization".

This point is significant because "prolonged" or "chronic grief" has been a long standing criterion for pathological grief reactions (Bowlby, 1981; Lindeman, 1944; La Roche et al. 1982; Lazare, 1979; Parkes & Weiss, 1983). It is necessary to distinguish between chronic grief and the normal prolongation of grief that has been referred to above. Our understanding of normal prolonged grief must be developed more clearly if we are to fully comprehend the full spectrum of the grief experience.

The results of this study provide evidence to suggest that a form of grief is indeed experienced by parents even after grief has been resolved. Parents indicated that grief remained but in a more bearable, less intense form. As such grief is not necessarily prolonged, it is leftover. Grief, in an altered form, is a remnant of grief, and it may continue to exist and to change in its nature over time. It

is critical to note that grief, as it is described here, differs from the prolongation of the grief process referred to by Edelstein (1984) and Rando (1984). Rather grief is seen as a entity that remains after the loss and grief process have been resolved. Furthermore, as the results of this study have demonstrated, grief is not only associated with sadness, it is also a part of the lost infant. As such the remnant of grief has a unique importance to bereaved parents, particularly when the short length of the infant's life limits the amount of shared time and memories.

Vulnerability

Vulnerability was a lasting remnant for many of the parents in this study. Parents were left with an increased sense of their vulnerability to loss and a feeling of dread at the prospect of experiencing loss again. Some theorists might argue that the underlying element of this kind of vulnerability is anxiety; fear of another loss and fear of the suffering that would accompany that loss. Anxiety is a well documented component of the grief response (Bowlby, 1980; Lindemann, 1944; Parkes, 1972; Parkes & Weiss, 1983). Yet, like grief, the persistance of anxiety following loss can be symptomatic of pathological grief. Parkes and Weiss (1983, pg. 131) state the trauma of loss can "create reticence and fear that may become overpowering in nature".

It is important to note that there is a significant difference between debilitating anxiety and a lasting sense

of vulnerability. While anxiety has been discussed at length in the grief literature, the notion of vulnerability as an enduring aspect of grief has received very little attention. In particular, the concept of continued vulnerability has not been well developed within a normative context. Edelstein (1984, pg. 14) points out that anxiety "is a response to the full realization of the death and the threat to ones security". According to Edelstein, this anxiety is part of the grief response.

In addition, the author describes a fear in many of the women she studied, of experiencing the intense emotions of grief. Rando (1984, pg. 237) has reported a similar occurance in dying patients, "as patients contemplate their losses ... there is a fear that they will be unable to tolerate the attending sorrow". These feelings of threat and fear are construed as a difficult, but expected phenomenon for bereaved mothers and dying patients. No mention is made however, of the long term impact of these "realizations" and "fears". According to the parents in this study, the realization that "this can happen to me" does not vanish, nor does the feeling of dread at the prospect of another loss; hense, the continued sense of vulnerability. However, this vulnerability would not be considered abnormal or pathological, even though it has persisted beyond the first year of bereavement for many parents.

Vulnerability has also been discussed as a by-product of unexpected and untimely loss. Parkes and Weiss (1983) argue that following such a loss the world seems less secure and trustworhty and that the bereaved person's assumptions about the world and his control over it, may be altered. This belief was substantiated to a high degree by the parents in this study. However, it was not presented as a debilitating insecurity, rather, it was simply a lasting understanding about the possiblity of personal loss. Parkes and Weiss assert that the implications for care in this circumstance include: increasing security, and reducing the sense of helplessness. This is most certainly a desirable goal, however, short of inducing amnesia, one cannot erase the knowledge gained and retained by parents who have experienced the loss of an infant. That knowledge remains as a lasting vulnerability. We do not know the long-term or permanent implications of this kind of vulnerability. Before that can be determined, this lasting remnant of grief must be explored further and clearly delineated within a normative framework for grief.

A few parents identified a feeling of vulnerability to exposing their grief reactions to the outside world. Rando (1984) suggests that this fear of loss of control and breaking down may interfere with the grief process. Again, one would not argue with that point of view. Instead, one would ask what is the significance of this behavior when it

remains with parents after resolution has occurred? In her study on dysfunctional grieving related to childbearing loss, Harris (1984) identified the "Normalcy Facade" as a characteristic of dysfunctional grief. According to Harris, this facade, in the early stages of grief, serves to maintain a normal front for the bereaved individual. Rather than acting "crazy" or grieving, the bereaved parent attempts to act normally. Acccording to Harris, this behavior is associated with a delayed grief response. What then does this behavior suggest when it is present after one has experienced grief and its resolution?

Possibly, it does represent a need to maintain a sense of normalcy, or perhaps privacy. From the responses of the few parents who commented on this particular sense of vulnerability, it would appear that the need to control public displays of grief stem from both possibilities.

Clearly, this discussion of vulnerability, presents a perspective on this lasting remnant that is highly compatable with a normal grief response. There is a need however, to gain a better understanding of this phenomenon in terms of its relationship to the longterm outcome of grief.

Cognitive remnants

The domain of cognitive remnants is an area in which current grief theory has provided some degree of theoretical structure to the normal remnants of grief. The cognitive

remnants identified in this study have been described elsewhere in the grief literature, within a normative context. For example, a continued sense of association with the lost infant following loss by SIDS has been demonstrated by Rubin (1982). Many researchers have identified the sense of increased appreciation for the experiences and people in one's life which result from loss and grief (Benoleil, 1985; Edelstein, 1984; Helmrath & Steinitz, 1978; Martocchio, 1985). Likewise, personal growth has long been recognized as a positive outcome of loss and grief (Berezin, 1982; Miles & Perry, 1985; Parkes, 1972; Parkes & Weiss, 1983; Rando, 1984). Finally, many researchers report on the significance of finding meaning in one's loss as a significant determinant of bereavement outcome (Benoleil, 1985; Davidson, 1985; Kastenbaum, 1981; Miles, 1985; Parkes, 1972).

All of the above have been offered as normal and expected sequelae of grief. In some cases, these lasting remnants have been used as indicators for measuring the degree and quality of resolution. For example, Davidson (1985) and Hagan-Arnold and Gemma (1983) suggest that the adaptation to loss will be incomplete until one can experience one's loss in the context of meaning. There is therefore substantial support for the inclusion of cognitive remnants such as those described above within the model for the normal lasting remnants of grief.

Affective remnants

A great deal of controversy exists within the literature with regard to the affective sequelae of grief. Many researchers have struggled with the reality that affective remnants of loss and grief, and their longterm impact upon the individual, are at best, difficult to measure and interpret. Nonetheless, more that any other category of remnant, affective residuals are highly suspect as indicators of abnormal grief or pathology.

It is emphasized that this suspicion is not without empirical justification. Feelings of sadness, anger, guilt, helplessness, and injustice are all recognized as normal components of the acute grief response (Berezin, 1982; Bowlby, 1981; Hutti, 1986; Lindemann, 1944; Miles & Demi, 1984; Miles, 1985; Parkes, 1972; Peppers & Knapp, 1980). However, the persistence of these feelings, or extremes in the expression of these feelings have been associated with disturbances in grief and its resolution by a number of researchers (Condon, 1986; Corney & Horton, 1974; Harris, 1984; Lundin, 1984; Miles, 1985; Miles & Perry, 1985; Parkes 1972; Parkes & Weiss, 1983).

As writers such as Parkes (1972) and Hartz (1986) have suggested, the controversy stems from the fact that abnormal grief responses are often a prolongation of normal grief or normal symptoms of grief exhibited in the extreme. The results of this study indicate that feelings of anger,

sadness, guilt, helplessness and injustice were among the lasting remnants of grief, even though parents believed their grief to be resolved. These findings provide some evidence to suggest that certain affective components of grief may linger, years after the loss has occurred and that this is a normal occurrance. Frantz (1984) supports this view saying that normal, healthy individuals may continue to exhibit strong affective behavior years after experiencing the loss of a child.

Few grief theorists would dispute this fact. However, at present, there is little in the way of theoretical structure to guide one's understanding of these particular remnants of grief, or how they impact on the long term experience of loss, particularly within a normative context. Miles and Demi (1984) are among the few who have attempted to construct a theoretical model that looks at one particular remnant, that of guilt.

The development of a framework such as the one identified in the current study would provide further direction for our understanding of the lasting affective components of grief. In addition, it would enable one to distinguish more clearly between affective remnants that reflect normal versus abnormal grief responses.

Secondary Remnants. The secondary remnants of grief appear to be highly interrelated with regard to the infant and parenthood, and the events and caregivers. In order to

provide a more integrated discussion of the secondary remnants of grief, they have been grouped together so that the remnants of the event and the caregiver will be considered jointly. Likewise, the lasting remnants of the infant and the self-image as parent will be examined together.

The event and caregiver

Parents in this study were left with several remnants of the events that surrounded the time of their loss. Urgency, lack of preparation, lack of time, loss of control, and a lack of reality remained as lasting impressions of that time. All of these experiences have been well documented within the perinatal grief literature (Davidson, 1985; Edelstein, 1984; Gardener & Merenstein, 1986; Miles & Perry, 1985). In addition, several grief therorists have demonstrated an association between the experiences listed above and poor grief outcome.

In a study of grief following stillbirth, Condon (1986) identified sudden, unexpected loss as a factor in the development of a pathological grief response. Parkes (1972) and Parkes and Weiss (1983) have suggested that unexpected loss may have a profound and negative impact upon the recovery of bereaved individuals. Miles and Demi (1980) demonstrated increased guilt in parents whose children died suddenly and unexpectedly. Sanders (1979-80) found a more intense grief response in relation to sudden loss, however,

the difference was not statistically significant. This lack of a significance may be attributed to the fact that the criterion for sudden-loss was considered to be seven days after the onset of illness. One wonders what the results might have been had the criteria for sudden-loss been hours after death rather than days.

With regard to the experience of loss of time, control and reality, there is little in the literature to describe the implications of these experiences for bereavement outcome. However, the work of Affonso (1977) and Stolte (1986) on "missing pieces" may provide some direction. In a study of the post-partum feelings of mothers, Affonso (1977) found that rapid labour and unfulfilled expectations contributed to a cognitive loss of certain aspects of the childbirth experience. Building on Affonso's work, Stolte (1986) also demonstrated the existance of missing pieces for postpartum mothers and questioned whether or not this phenomenon could interfere with the immediate tasks of mothering. One could postulate that the remnants described by the parents in this study might be viewed in a similar fashion to the "missing pieces" described above. Taking this a step further, one could also suggest that "missing pieces" associated with the events surrounding the loss of an infant might interfere with the parent's ability to assimilate and deal with loss.

Based on the discussion thus far, the factors

associated with the events surrounding the loss of an infant have the potential to complicate the grief experience and response of parents. Nonetheless, the findings of this study show that these factors also remain with many parents after the resolution of loss has occurred. Parents described these remnants, not as ongoing and disturbing, but as "simply there" when they thought about the total experience. It is reasonable therefore to include these remnants of the events surrounding loss as part of a model depicting the normal lasting elements of grief. It is also necessary to include this particular remnant for we do not know what the long-term impact of these lasting impressions might be. Before that can be determined, the events surrounding loss must be clearly delineated in terms of their relationship to the concept of resolution, rather than their relationship to the non-resolution of grief.

Similarly, the lasting remnants of the caregiver must be considered within a framework for normal grief. The findings of this study indicate that parents maintained positive and negative lasting impressions of the caregivers encountered at the time of loss. This finding is supported by the work of Condon (1986) who believes that recollections of the emotional climate, especially reactions of staff, are more accurately retained than verbally transmitted information received at the time of loss. In like fashion,

Miles and Perry (1985) believe that the negative aspects of care are remembered a long time after the loss has occurred.

The literature quite clearly indicates that behaviors of the caregiver, particularly behaviors that are perceived negatively by parents, may have profound and far-reaching effects on the outcome of parental grief. For example, Geller (1985) examined a case study of abnormal grief following the loss of a child, and attributed the prolonged and dysfunctional grief response to the "iatrogenic interdictions" of the caregivers. Following a survey of 61 families who had suffered the loss of a child, Segal et al (1986) suggested that profound effects can be seen as a consequence of the attitudes and behaviors of healthcare professionals. Likewise, Davidson (1985) has argued that the attitudes of staff may have a profound, negative effect on grief outcome for bereaved parents.

Given the caregivers potential to impact upon the outcome of parental grief, it is disturbing to note the number of clinicians and researchers who continue to identify insensitivity, discomfort, avoidance and withdrawl on the part of those who care for parents following the death of an infant (Gardner & Merenstein 1986; Carr et al., 1985; Davidson, 1985; Estok& Lehman, 1983; Hodge & Graham, 1985;). The findings of this study provide further evidence to support the above observations. In addition to positive

lasting impressions of the caregiver, all parents were left with lasting impressions of a "failure to care" on the part of the caregiver.

The literature suggests that these negative impressions may have impeded the progress through grief for these parents. Far less clear however, are the implications for these lasting impressions when they remain with parents over time, after resolution has been reached. Again, like so many of the remnants discussed thus far, these lasting remnants of the caregiver are not vivid, ongoing, distressing recollections; rather, they are simply the impressions that have remained with parents. It is important to note however, that both positive and negative impressions continued to be meaningful to parents. As such, the lasting remnants of the caregiver must be identified and carefully considered as part of the normal grief response. The fact that the remnants of "They" may not exist or be exhibited in a dysfunctional way, does not mean that they are unimportant. These remnants may remain in a "normal" sense and yet still have the potential to impact upon parents. For example these normal remnants could have powerful implications for future encounters with "They", but go unrecognized because they are not manifested in an abnormal fashion.

It is clear that the events and caregivers encountered at the time of loss have the potential to greatly influence

the course and outcome of grief. The findings of this study provide some evidence to suggest that the lasting remnants of the events and caregivers also remain with parents as normal residuals of the loss and grief experience. Although these elements exist within a normal framework for grief, they continue to have the potential to impact, both positively and negatively on the attitudes and behaviors of parents.

The infant and self-image as parent

All of the parents in this study retained lasting impressions of their infant via the images, feelings, memories and mementos associated with the time shared with that infant. This finding is consistent with the results of others. Edelstein (1984) surveyed 130 women who had experienced the sudden and unexpected death of a child. Edelstein found that mothers selected and retained "frozen frames", or lasting visual images of their lost child. Hagan-Arnold and Gemma (1983,pg.103) confirm the importance of memories, believing that they serve to "keep the dead alive". Davies (1987) demonstrated that memories and mementos have unique meanings for parents and can serve to maintain lasting impressions following the death of their child. Based on these findings, there is evidence to support the assumption that many lasting remnants of the infant remain with parents at the point of resolution and beyond.

Condon (1986) suggests that the ability to mourn and to

resolve loss is dependent upon the capacity to evoke stable, consistent memories, images or mental representations of the lost object. It follows that these elements will not simply dissappear after resolution has been achieved, but will remain with parents well beyond that point. Nonetheless, researchers such as Parkes (1972) and Parkes and Weiss (1983) have demonstrated an association between continued preoccupation with the deceased and a pathological grief response. Unfortunately, as Edelstein (1984) points out, there is a propensity among healthcare professionals to look suspiciously upon any sort of preoccupation with lasting images of the deceased. Grief theorists have argued that years after loss has occurred, some preoccupation with the deceased is common, and normal, and may be present without symptoms (Rando, 1983; Rubin, 1984). However, in general, current grief theory does not clearly develop the concept of lasting images of the deceased within a normative framework. We have yet to clearly define or understand what the normal remnants of the infant are for parents whose baby has died in NICU. Nor have we begun to comprehend the complex meaning and implications of those remnants.

The complexity of these remnants of the infant has been illustrated quite clearly in the results of this study. According to Miles and Perry (1985), at the point of reorganization, parents are able to remember their child with less pain and are able to focus on happy memories.

It follows that at the point of resolution, happy memories would be part of the lasting remnants of the infant. However, in the case of the parent whose infant dies in NICU, happy memories take on a different meaning than that referred to by the authors above. For example, one mother treasured a picture of her dead infant. This was her "happy" memory. For another mother, the "happy" memory was a precious moment holding her dying infant. For NICU parents, these are often the kinds of happy memories that remain of a short life that was associated with so many unhappy and unpleasant moments.

In spite of this, the parents interviewed in this study, maintained that there were good and special remnants that remained along with the more tragic remnants. If one of these parents were to share one of the "happy" memories described above with a caregiver who had a propensity to be suspicious of a lasting preoccupation with the deceased, one can easily imagine the conclusions that would be drawn. The conclusion of "possible dysfunctional grief" might be reached because there are no clear guidelines for the interpretation of this unique kind of lasting remnant. This illustration underscores the need to explore more fully the lasting remnants parents carry of their infant, and the cognitive and affective implications of those remnants, within a normative framework.

Just as the lasting remnants of the infant take on a

unique complexity for this group of parents, so do the lasting remnants of the self-image as a parent. According to Estok and Lehman (1983), following the death of an infant, parents have had little time to take the baby in, thus making identification with that infant difficult. The results of this study provide evidence to the contrary in that the majority of the 14 parents interviewed recognized a sense of identification as a parent to the dead infant. In all but one case, the infant's life span was defined in a few short hours or days. The finding that mothers' maintained a stronger sense of attachment and parenthood than fathers is consistant with the work of Mahan et al (1981) and Rando (1983). Many theorists have studied and identified the quality and strength of the attachment parents hold for the unborn child (Condon, 1986; Klaus & Kennel, 1982; Rando, 1984; Weaver & Cranley, 1983;) The findings of this study are consistent with this view in that the majority of parents identified feelings of attachment and parenthood to their lost infant.

Certain factors make the lasting impressions of parenthood unique for parents who have suffered a neonatal loss. Key aspects of the remnant of parenthood that must be considered are intensity and duration. In their classic works, Parkes (1972), and Bugen (1977) have identified security and centrality of the relationship as determinants of the duration and intensity of grief. With very limited

exposure to their living infant, the parents in this study experienced a significant grief response following the death of their infant. The results have clearly shown, that even at five years post-loss, parents continue to carry many significant and lasting remnants of their loss. These findings are contrary to the theory proposed by Parkes and Bugen and could therefore be interpreted as an inappropriate grief response. Based on this theory, one might easily question the intensity of grief experienced by these parents, as well as the lasting sense of parenthood that remained. However, the literature on perinatal bereavement has clearly shown that parents who experience the death of a newborn may indeed exhibit a profound grief response (Bourne & Lewis, 1984; Edelstein, 1984; Ewy & Ewy, 1984; Giles, 1970; Helmrath & Steinitz, 1978; Hutti, 1984; Kennel et al., 1970; Lewis & Page, 1978; Schiff, 1977). Thus, the parents in this study are exhibiting lasting remnants that are unique to a normative framework for perinatal loss.

The lasting remnant of the self-image of parenthood is significant in another sense. Research has shown that the nature of the relationship with the deceased has significant implications for the grief response and for grief outcome (Parkes, 1972; Parkes & Weiss, 1983; Rubin, 1984). Furthermore, most of the grief theorists believe that part of grieving entails the re-defining of self in relationship to the deceased (Benoleil,1985; Estok &

Lehman, 1983; Lindemann,1944; Parkes, 1972; Parkes & Weiss, 1983; Rubin, 1984). Rando (1984) states that one of the tasks of grieving is to re-define one's own identity to reflect reality. Yet, as indicated above, the majority of parents continued to hold a lasting relationship as parent to the dead infant. This is a lasting remnant. Nonetheless, some might argue using Rando's criteria, that not all the tasks of grieving have been accomplished. It follows then, that, the lasting impression of parenthood might be construed as an unresolved element, rather than a normal remnant of grief.

No one would suggest that the resolution of grief demands that one totally withdraw from the relationship to the lost person. Yet, the underlying mandate to distance oneself from the deceased is present as a prerequiste to normal resolution. For example, Bowlby (1980) and Parkes (1972) believe that searching behavior serves the purpose of "unlearning attachment" to the deceased. It would appear however that the remnants of parenthood serve to maintain a sense of attachment and a feeling of closeness to the lost infant. Researchers and clinical therapists stress that parents keep their infant alive through the memories they hold, and that parents will always continue to care for their child despite death (Frantz, 1984; Hagan-Arnold & Gemma, 1983). At present, we are limited in our understanding of the complex nature and meaning of the

continued sense of relationship parents hold following the death of an infant, particularly when the infant dies immediately after birth. The findings of this study have resulted in the development of a theoretical schema which through further development, would allow one to examine and understand the remnants of parenthood from a perspective of normalcy.

It is possible that our current limited perspective on the remnants of parenthood has contributed to the occurrance of "hidden parenthood". Parents may recognize that their "internal" reality of parenthood will not be understood or validated by those around them. Thus the dilemma arises as to whether one will deny one's child and one's sense of parenthood, or whether one will project the "external" image of normalcy that seems to be expected. This exemplifies a common theme that was identified from the data, which was the "keeping and sharing of secrets" about parents' loss and grief. Parents in all the groups described episodes of either keeping or sharing the details of their loss and feelings. Sharing "secrets" had positive outcomes in that parents were able to validate their loss, learn from the experience of others, receive comfort. and gain insight into their own emotions. However, keeping "secrets" served the purpose of protecting and normalizing parents in the eyes of those who might not be comfortable with or accepting of their loss and feelings.

The phenomenon of "hidden parenthood" is a normal lasting remnant for parents following the death of an infant. It appears however that this remnant may be in part, a by-product of our failure to understand and accept the ongoing significance and meaning of the relationship that exists for parents in relation to their dead infant. Likewise, "hidden parenthood" may be a reflection of the societal discomfort with death described so well in the literature (Kalish, 1985; Kastenbaum, 1981; Rando, 1984). There is a need to broaden our knowledge of this normal remnant of loss and grief so that the dilemma and discomfort of "hidden parenthood" may be minimized for bereaved parents.

At present, current grief theory offers little guidance for our understanding of the remnants of the infant, the self-image as parent, or the lasting relationship that exists in the mind of parents following the loss of an infant. Nonetheless, these phenomenon have tremendous potential to impact upon bereaved parents. Therefore, further research in this area is essential.

A New Model for the Resolution of Grief

In the preceding sections, several gaps in current grief theory were identified in relation to the concept of resolution and the lasting aspects of grief and loss that remain with parents following the death of an infant. In this section, a new model for the resolution of grief is

presented as a beginning step in the further development of grief theory. One of the questions posed in this study asked what is the pattern of grief observed in parents following the loss of an infant? The model presented here is offered as a tentative reflection of the pattern of parental grief following the death of an infant in NICU. It is emphasized that the model is not in conflict with the current theoretical view, rather, it builds upon that theory to expand the scope of our current thinking. It is further emphasized that this model is based on exploratory, descriptive research and therefore requires further development, testing and validation.

The Traditional View

Traditional theory presents the concept of resolution as an end point to the grief process. In Bowlby's (1980, pg.85) framework, the final stage of mourning is the "phase of greater or lesser degree of reorganization". It is characterized by acceptance of the loss as permanent and shaping life anew. According to Lindemann (1944), the end point of grief is marked by emancipation from bondage to the deceased, readjustment to life without the deceased and the formation of new relationships. In their classic book entitled "Recovery from Grief", Parkes and Weiss (1983, pg. 155) maintain that recovery is demonstrated by: "intellectual and emotional acceptance, and by the changing of one's model of self and the outer world to match

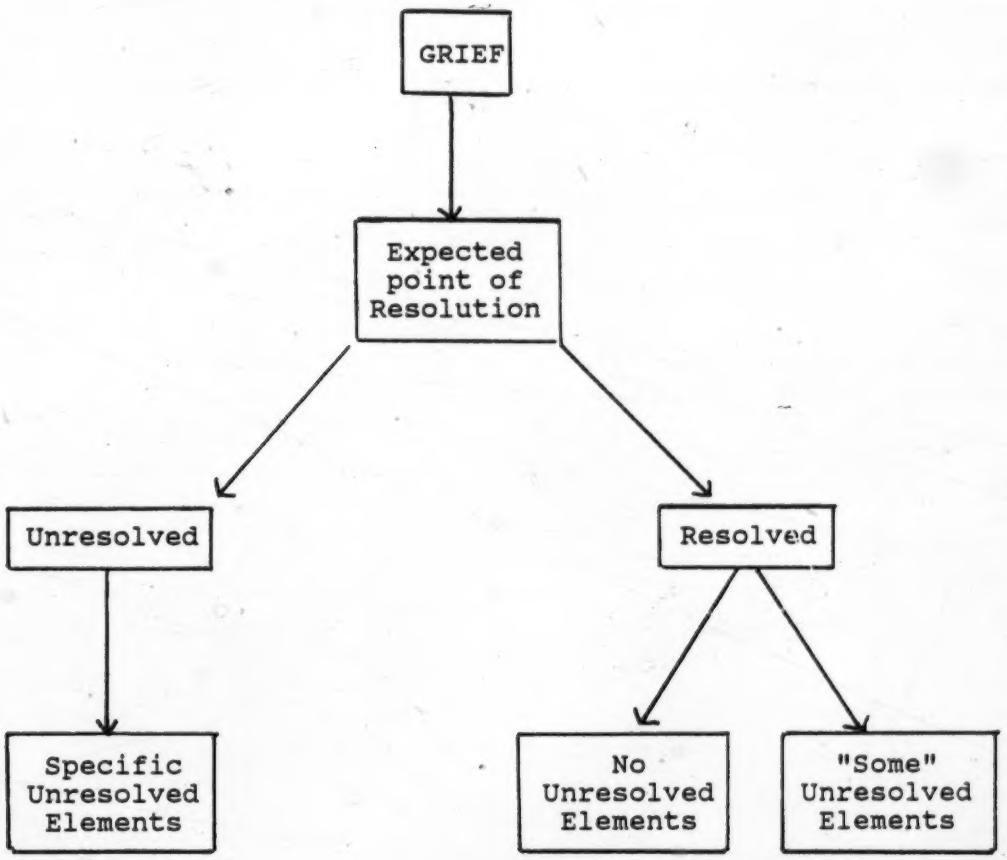
reality". Finally, Edelstein (1984, pg.15) has summarized the the work of several grief theorists to produce a three-stage model for maternal bereavement. The final stage in the model is labled "reorganization" and is described as a "modified equilibrium resulting in an alliance with the past and ongoing activities: loss is integated into life".

In each of these theories, the conceptualization of the enduring elements of grief would take one of the three forms depicted in Figure 3. First, some aspects of the loss and grief experience that remained after a given time would be labelled as unresolved and therefore considered as abnormal. If these unresolved, abnormal aspects of grief are present, it can be determined that grief is unresolved, and that the wellbeing of the individual is in jeopardy. Without question, a number of excellent studies have demonstrated the truth to this theoretical perspective (Condon, 1986; Corney & Horton, 1974; Drotar & Irvin, 1979; Lewis & Page, 1978; Parkes, 1972; Parkes & Weiss, 1983; Turco, 1981).

The reality of unresolved grief and its significance for the long-term outcome and wellbeing of the bereaved is not in question. What is being challenged however, are the other alternatives that are available in the current model of grief. Grief could be completely resolved with no lasting unresolved elements. Most grief theorists would reject this conclusion as an unlikely outcome in the case of significant

Figure 3

A Traditional Model for the Resolution of Grief



loss. Furthermore, as Rubin (1984) points out, the absence of psychopathology does not necessarily imply that all aspects of the loss have been worked through.

The last alternative is that the bereaved individual may be resolved to their loss but certain aspects of the loss may be unresolved, may linger, and may never be dealt with. There is a real lack of clarity and structure in traditional theory with regard to what these various remaining aspects might be and what the immediate and long-range implications of these phenomenon are within a normative context. It is this lack of clarity that has created some of the difficulties in interpreting the lasting remnants identifed in the previous sections; for example, the confusion over the significance of lasting images of the lost infant or the continued experience of grief itself after resolution has occurred. The traditional theoretical model provides little or no direction for understanding the normal lasting remnants of grief. Therefore, the current conceptual framework must be expanded to meet this need.

An Expanded View

Grief is a natural human response to loss. It is comprised of certain cognitive, affective and behavioral phenomenon which are concomitant with the significance and meaning of that loss. Based on the findings of this study, it is proposed that resolution, rather than an end-point to grief, is a continuing process of integrating and dealing

with the primary and secondary remnants of loss and grief. The nature and meaning of these remnants continue to evolve just as the nature and meaning of resolution appears to change with the passing of time.

These dynamic remnants may be similar to the unresolved elements of grief that signal an unhealthy response to loss. However, through their structuring and clarification, within a normative framework, these remnants would be clearly distinguishable from those which have been shown to undermine the psychological, emotional,and physical wellbeing of bereaved individuals. A new model for the resolution of grief is presented in Figure 4. Rather than conceptualizing the normal lasting elements of grief as "something unresolved", they are presented as predictable, ongoing remnants of loss and grief. As such, they are able to impact upon and shape the essence of resolution for each individual. Rather than vague leftovers, each lasting remnant can be identified and understood in relation to the other remnants within the context of resolution as a whole.

It is hypothesized that certain remnants may be interdependant in their relationship to, and influence upon the state and meaning of resolution for each individual. Figure 5 illustrates how the "new model" could be further developed to test this hypothesis. Comparing the scenarios presented, one can see where one remnant would interact with another, and how together, they could shape the state of resolution and its meaning for the individual.

Figure 4

An Expanded Model for the Resolution of Grief

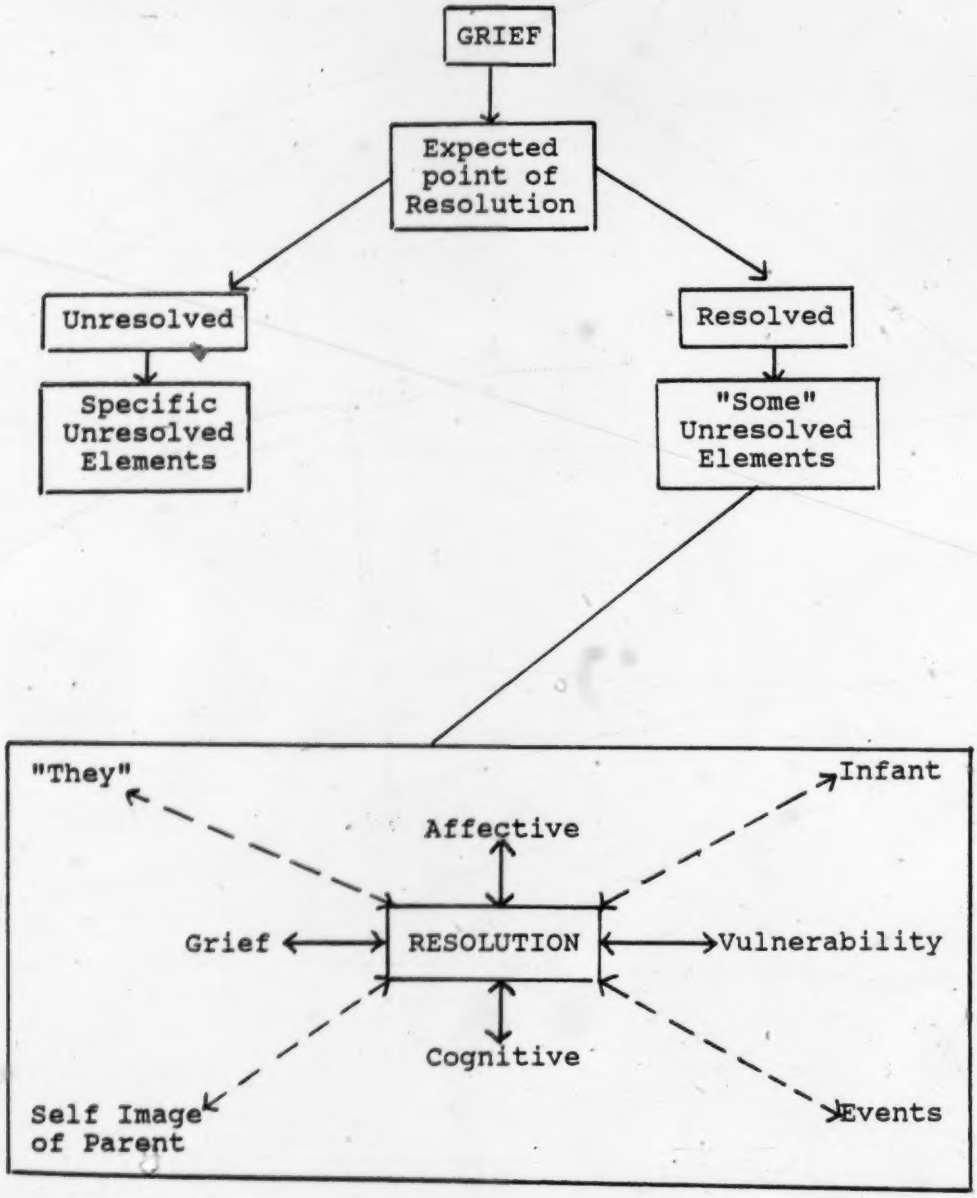
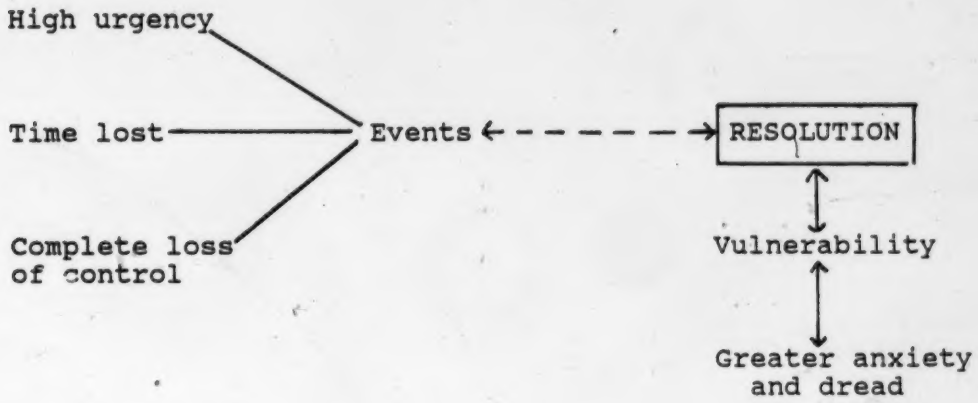


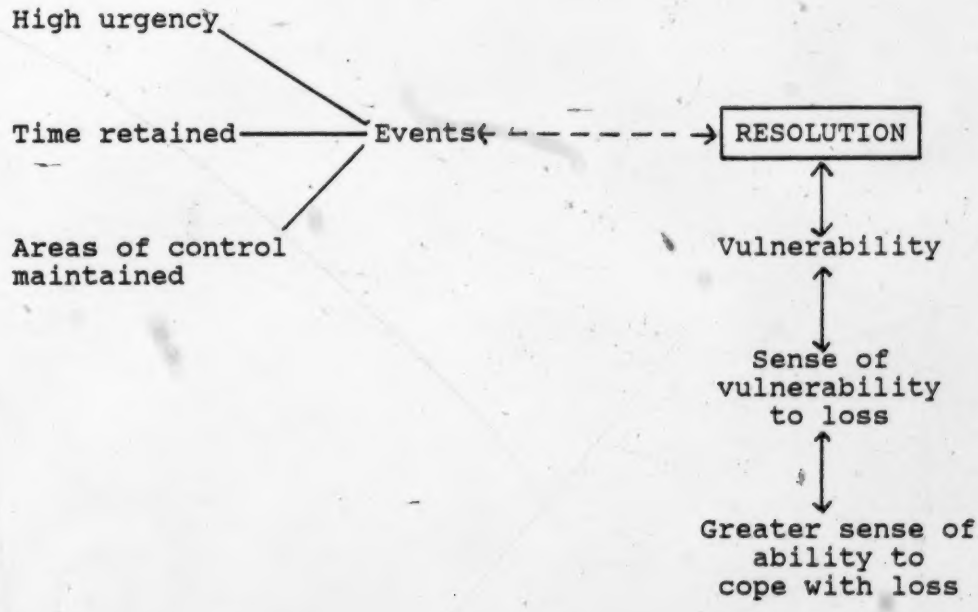
Figure 5

An Interactive Model for the Remnants of Grief

A)



B)



As the model in Figure 5A depicts, high urgency, a sense of lost time and feelings of loss of control, may interact to heighten the sense of lasting vulnerability. Together, these remnants would have the potential to alter the experience of resolution. In Figure 5B, it is suggested that the lasting sense of vulnerability may be lessened by parents having experienced a greater sense of time and control during the events that surrounded their loss. Once again, these remnants might interact with one another to impact upon the state of resolution.

Implications for Nursing and Further Research

The intent of this exploratory, descriptive study, was to examine the phenomenon of resolution of parental grief, with a view to the generation and development of grief theory. The concepts and theoretical models that evolved from this work must be subjected to considerable testing and validation through further research before they can be incorporated into the practice of nursing with any degree of confidence. Nonetheless, the findings of this study raise several questions that have immediate significance for nurses caring for parents who suffer the loss of an newborn in NICU or who have the potential to suffer such a loss. These questions will be discussed, along with the directives for future research, in the following sections.

Significance for Nursing Practice

Miles and Perry (1985) stress that critical care

nurses play an important role in determining the experiences of parents whose children die. They believe that at this time of great distress and shock, the interventions of nurses may have a significant impact on the overall grief outcome for parents. The findings of this study provide more information as to what that impact might be and how it might be manifested.

The immediate significance of the findings to the practice of nursing is that they increase our awareness of the lasting impressions parents carry from their experience of loss. The importance lies in our ability as nurses to impact upon the primary and secondary remnants that are retained. Nurses who care for parents whose infant is critically ill and subsequently dies have the potential to alter and shape those remnants to a high degree. For example, nurses who care for a dying infant must be aware of the influence they exert over the parents' lasting impressions of that infant, both negative and positive. Edelstein (1984) describes the "frozen frames" mothers retain of their lost children. She maintains that the "frames" of the time of death may be particularly disturbing and lingering for parents. Nurses who interact with parents at the time of their infant's death need to be aware of the long-term significance of that event and look for ways to optimize that experience for parents.

A lasting and significant remnant for parents seems to be the way their infant was handled and cared for by nursing staff. In this area, nurses have unlimited opportunities to create positive lasting remnants simply by giving gentle, considerate, compassionate care to the infant.

The significance of holding the infant, particularly for mothers is of importance to nurses. This is especially so with regard to holding the infant while alive. Researchers have demonstrated the importance of parents seeing and holding their infant after death (Lewis & Page, 1978). Little is known however about the significance of holding during life. Often, NICU nurses are reluctant to disturb the critically ill newborn for fear of worsening the babe's condition. However, based on the findings of this study, nurses must take a closer look at the importance of holding one's living child to a parent who must pack a lifetime into a few moments. This is particularly important if those moments are indeed a lasting remnant that will continue to play a role in the overall resolution of that parent's grief.

Through the provision of information, support and guidance, nurses may be able to enhance the quality of parent-infant contacts and interactions, thereby promoting more positive remnants of parenthood. Interventions such as these may be particularly helpful in strengthening fathers' sense of parenthood. Likewise nurses are in an ideal

position to help parents create more meaningful "happy memories". Nurses could ensure that no parent was left with only an autopsy report or hospital name-band to serve as concrete mementos of their infant.

Perhaps, more than any other remnants, nurses have the capacity to create more positive and comforting lasting impressions of the events that surround the loss and of the themselves as caregivers. For example, through their efforts to alter the nature and impact of the events surrounding loss, nurses could also reshape other remnants such as vulnerability. As the model in Figure V demonstrates, interventions which alter the events surrounding loss have tremendous potential to positively influence the state and meaning of resolution for parents.

With an increased awareness of the lasting remnants of the event, nurses can seek and develop ways of reducing the parent's sense of urgency, unreality, sense of lost time, and loss of control. These factors are often an unavoidable reality when an infant is born with a life threatening problem. Because of this reality, nurses must be more sensitive to the lasting impact of these events and must actively intervene to minimize the "nightmare" and maximize control for parents wherever possible.

The parents in this study identified many positive and comforting lasting remnants of their caregivers. At the same time, there remained many remnants of isolation, hurt,

anger and confusion which were also associated with the caregiver. Often, this caregiver was a nurse. The implications for nursing practice and nursing education are clear with regard to this particular remnant. Nurses must recognize their own ability or inabilty to interact in a meaningful and theraputic way with bereaved parents. We must identify our strengths and weaknesses both individually and collectively and begin to develop strategies which will enable us to provide skillful and compassionate care to parents prior to and following the loss of an infant. This begins with nursing education and the development of a nursing curriculum which provides a solid theoretical background for understanding the dynamics of the human grief response. In addition, nurse educators must seek out and maximize clinical learning opportunites which would allow nurses to become more comfortable with death and grief, and which would enable nurses to develop their skills in caring for individuals who have suffered significant loss.

These actions are essential if we are to meet the immediate needs of bereaved parents as well as impact on the long-term outcome of grief. As nurses, we must begin to examine our own behaviors with a view to the lasting remnants that may remain with parents and the potential impact those remnants may have for future encounters with healthcare professionals. If the predominant remnants of "they" are centred on withdrawl, isolation and abandonment,

the future development of therapeutic relationships with nurses or other healthcare professionals may be adversely affected. The findings of this study suggest that this need not be the case if parents maintain positive and comforting lasting impressions of their caregiver.

Directives for Future Research

From the results of this study it has been suggested that the meaning and experience of resolution changes as time passes for parents who have suffered the loss of an infant in NICU. Further research is needed with larger samples of bereaved parents, over a longer timeframe to validate this conclusion and to enable us to develop our understanding of this characteristic of the resolution of grief. Additionally, more work needs to be done with regard to the resolution of grief in the siblings of infants who die in NICU. The following questions need consideration:

1. What is the unique experience and what are the characteristics of resolution at 10 years post-loss and beyond?

2. What is the meaning and nature of the resolution of grief for children whose sibling has died in NICU?

3. Does the meaning and experience of resolution differ for other groups of bereaved individuals; for example parents who have suffered the loss of an infant through stillbirth or sudden infant death syndrome?

Confusion continues to exist within the grief literature as to how to define and distinguish between the normal and abnormal lasting sequelae of grief. A model was developed, based on the findings of the current research, which presents several enduring elements of the loss and grief experience within a normative framework. Further research is needed to test the viability of this model. Some differences seemed to exist in the lasting remnants held by mothers and fathers. This phenomenon needs to be studied in greater depth. Likewise, more research is needed to determine what the lasting remnants of grief are for surviving siblings. Once again, several immediate questions arise:

1. What other lasting elements of grief might also exist that could be added to the proposed framework for normal lasting remnants of grief?

2. How do the lasting remnants of grief differ between fathers and mothers? What are the implications of these differences for the marital relationship and for the long-term outcome of grief?

3. What are the lasting remnants of loss and grief held by the siblings of an infant who dies in NICU?

4. Do the normal lasting remnants of grief differ between specific groups of bereaved individuals? If so, how do they differ? What might the implications for care be in these different situations?

Figure 5 provides an example of how one remnant could hypothetically interact with another to jointly influence the state and experience of resolution. Further research is needed to test the validity of this assumption. Questions that would guide this research include:

1. Do interactive relationships exist between the lasting remnants of grief?

2. How do the lasting remnants impact upon one another to shape and alter the experience of resolution for parents following the loss of an infant in NICU?

3. What specific interventions will have a positive impact upon the lasting remnants of grief?

4. Do the lasting remnants of grief have any long-term implications for the personal resources and wellbeing of bereaved individuals? If so, what are those implications?

Those who care for bereaved parents make decisions concerning the normalcy and the progress of their grief response. These decisions are the basis for the care and support provided and for the expectations communicated to the bereaved individual, the family system and to society as a whole. Clearly then, there is a need to gain a greater understanding of the phenomenon of resolution and the lasting remnants that remain with parents following the death of an infant. Further research based on the questions identified above is essential if we are to offer more knowledgeable, capable and compassionate care to bereaved parents.

Strengths and Limitations

This study was qualitative, exploratory and descriptive in nature. The purpose of this research was to expand theory and to develop concepts that would add to the understanding of the phenomenon of grief and its resolution. It would be inappropriate to attempt to generalize the findings of this study to a larger population of bereaved parents and to do so is not the intent of the researcher.

The results and conclusions of the study would have been strengthened if the same group of parents had been studied over an extended period of time, rather than different parents at three distinct times. Changes in the meaning of resolution could then have been recorded for the same individuals over time, thus increasing the confidence one had in the existence of that change as a characteristic of resolution. Unfortunately, limited time and financial resources precluded this particular design for the study.

The researcher was unable to obtain adequate numbers of three year parents. Therefore the unique contribution of this group was, in essence, lost. Fortunately, all of the one and five-year parents could be recruited thus allowing the investigator to contrast and compare the difference in responses of parents over an extended period of time.

Limited time and financial resources also precluded a second interview with each of the couples who participated in this study. Therefore the concepts and conclusions were

only validated with two couples, one of which was from the one-three-year group and one from the five-year group. While these two couples provided valuable direction for the further development of the concepts that were identified from the data, the findings would have been strengthened by the contributions of all the parents.

Finally, several parents declined to participate in this study for various reasons. Before any definitive statements could be made about the results of this study, more would need to be known about the differences that existed between parents who did participate and parents who did not. Possibly, the lasting remnants of loss and grief would differ between these two groups of parents. One must question therefore, are the parents who did participate reflective of the larger population of bereaved NICU parents? Further research in this area would prove most helpful in answering this question.

The limitations described above must be taken into consideration when evaluating the results of this study. Nonetheless, the findings and conclusions drawn from this work have resulted in the identification of several interesting and important ideas and questions for nurses to consider when caring for bereaved parents. In addition, a number of areas for future research have been identified for the further development and understanding of grief theory.

Summary

The purpose of this study was to examine the nature and duration of grief experienced by parents over time, following the loss of an infant in NICU. From this work, a new way of looking at the phenomenon of resolution and its relationship to the grief process was uncovered. Parents at one, three and five years all believed their grief to be resolved, yet several differences were identified in the exact nature and meaning of resolution for these parents. In addition, parents described many lasting elements of grief that remained even after their grief was perceived to have been resolved.

These finding were drawn together to generate a theoretical model for the resolution of grief and for the normal, lasting remnants of grief that parents continue to carry. These remnants were categorized as either primary or secondary, depending on their direct proximity to the grief response. It was postulated that these primary and secondary remnants had the potential to influence one another and to jointly impact upon the overall state and experience of resolution.

Several implications for the practice of nursing and for future research were identified.

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APPENDIX A

INTERVIEW GUIDE

APPENDIX A

Interview Guide

Demographic Data - Mother

Name: _____ Date of Birth: _____

Education: Number of years of school completed

Grade school	1	2	3	4	5	6
Junior High	1	2	3			
High School	1	2	3	4		
University	1	2	3	4	5	6
College	1	2	3	4		

Occupation: _____

Demographic Data - Father

Name: _____ Date of Birth: _____

Eduation: Number of years of school completed

Grade school	1	2	3	4	5	6
Junior High	1	2	3			
High School	1	2	3	4		
University	1	2	3	4	5	6
College	1	2	3	4		

Occupation: _____

Family Data:

Number of years in present relationship: _____

Name/Date of Birth of Living Children:

_____

_____

_____

Name/Date of Birth of Deceased Infant: _____

_____

Your total taxable family income last year was:

_____ Less than $ 5,000
_____ $ 5,000 - $10,000
_____ $10,000 - $20,000
_____ $20,000 - $50,000
_____ More than $50,000

Interview Questions

Note: These questions are intended to guide each interview; therefore the exact wording of the questions may be altered in any one interview in order to respond to the specific circumstances of that interview and that respondent.

1. To begin with, I would like to understand more about the situation surrounding your baby's life. Could you tell me about your experience?

   Probe:
   - How old was the baby (gestational age) at birth?
   - Did your baby go to NICU immediately?
   - Did you hold, see the infant prior to NICU admission?
   - What problems did your baby have?
   - What happened to your baby in NICU?

2. What was it like for you when your baby was in NICU?

3. How often were you able to see your baby?

4. What did you do during your visits?

   Probe: - Did you touch/hold/talk/give care?

5. What was that like for you?

6. What kind of relationship did you have with your baby?

Probe:
- Did you feel close to the baby?
- Did you feel like she was really yours?
- Did you have a sense of being her mother/father?

7. What happened the day the baby died?

Probe:
- Had you been prepared for that?
- Was it like you thought it would be?
- What was it like for you that day?

8. What was it like for you immediately after the baby died?

Probe:
- Some people talk about good days and bad days. Did you have those too?
- What were the bad days like?
- What was particularly difficult?
- What did you do on those bad days to feel better? Did anything in particular help?

9. How has that experience changed over time?

10. How did you get from that point to this one?

Probe:
- Have religious beliefs or beliefs about the world in general helped or hindered your progress?
- Some parents find their friends have played a role - did you find that to be true?
- Bereaved individuals use a variety of activities to help them (some become very active in community work, some use alcohol or drugs, some avoid contact). What activities were/were not helpful for you?

11. What are the things you now remember most often about

your baby?

Probe: - Are these also the things you remember most clearly?
- What situations/occasions prompt your memory?

12. What do you do when you remember?

Probe: - What are the feelings that come along with these memories?

13. Have these memories and feelings associated with them changed over time?

14. What does resolving or coming to terms with grief mean to you?

15. Would you say that you have reached a point where your grief has been resolved?

16. When did that happen for you?

Probe: - How has that happened for you?

17. What are the lasting feelings and thoughts that you have about your baby?

Probe: - How do you think these may change over time?

18. Overall, how has this experience affected you and your life?

Probe: - How has it affected how you see yourself/feel about yourself?
- How has it affected how you see your world (life in general, values, beliefs)?

19. Has this experience affected other members of your family? If so, in what way?

20. How has it affected your relationship with other family members - husband, children?

21. Based on your experience, what is it that you think is the most important thing for nurses to do when working with families who have been in your situation?

APPENDIX B

TEXAS REVISED INVENTORY OF GRIEF

Pages 154 and 155 have been removed because of the unavailability of copyright permission. The pages contained the Texas Revised Inventory of Grief.

Source: T.R. Faschingbauer (1981). Texas Revised Inventory of Grief: TRIG. Houston, TX: Honeycomb Publishing Co.

APPENDIX C

CONSENT FORM

APPENDIX C

University of Alberta
Faculty of Nursing

Informed Consent Form

Project Title: Parental Grief Following the Loss of an Infant in NICU: A Descriptive Study of the Nature and Duration of Grief

Principal Investigator: Sharon Morgan, B.Sc.N.
Graduate Office, Faculty of Nursing
3-119 Clinical Sciences Building
University of Alberta
Edmonton, Alberta T6G 2G3
(Home phone: 432-4606)

Supervisor: Dr. E. Davies (on sabbatical)

Faculty of Nursing Contact: Dr. P.A. Field
Phone: 432-6248

The major purpose of this study is to examine the grief experience of parents over time. In particular, the focus will be on the lasting thoughts, feelings and perceptions following the loss of an infant in NICU. This information will add to the knowledge about grief experiences of parents and will provide direction for the care and support of bereaved parents.

You will be asked to fill out a questionnaire about your past and present grief experience. The questionnaire will require about 10 minutes to complete. The principal investigator will then interview you together with your spouse for about one to one and a half hours. A subsequent short interview may be required to enable the investigator to clarify and better understand you comments. These interviews will be tape recorded to allow the investigator to accurately document your feelings and ideas. To protect your privacy, you will not be identified on tape and once the contents of the interview have been analyzed, the tapes will be erased. All information will be treated in a discreet and confidential manner. The data will be kept in a locked cabinet following the completion of the study. After a period of two years, all identifying information will be destroyed. The content of the interviews will be preserved for possible further analysis. A final report, containing

anonymous quotations will be available at the end of the study. In addition, a summary of the report will be shared with each respondent.

There may be no direct benefits to you for participating in this study, but your participation may be beneficial in its contribution to the care of other bereaved parents. If, following these interviews, you wish to have further contact with a qualified support person, the investigator will assist you in identifying potential resources.

This is to certify that the investigator has explained the purpose of the above study and the procedures involved therein. I _____ HEREBY AGREE to
(Print Name)
participate as a volunteer in the above project. I hereby give permission to be interviewed and that these interviews may be tape recorded. I understand that these tapes will be erased at the completion of the project and that my name will not be associated with any written material pertaining to this project.

I understand that I am free to withdraw from the study without penalty at any time. Furthermore, I understand that I have the right to decline answering any questions posed by the interviewer.

I have had the opportunity to question the principal investigator and all of my questions have been answered to my satisfaction. I am in possession of a copy of the information and procedures outlined in this consent.

_____ _____
Participant Date

_____
Researcher

APPENDIX D

LETTER OF INTRODUCTION

APPENDIX D

Sharon Morgan, B.Sc.N.
Graduate Office
Faculty of Nursing
3-119 CSB.
University of Alberta
Edmonton, Alberta
T6G 2G3

Dear Mrs. and Mr.

I am a graduate student in the Faculty of Nursing, University of Alberta. I am conducting research on the grief experience of parents who have lost an infant in the newborn period. In particular, the focus of the study is on the lasting thoughts and feelings related to this loss. Learning more about this experience from parents like yourself will add to our knowledge about parental grief and will provide direction for the care and support of bereaved parents.

I ask you to consider participating in the study. Should you agree, you would be required to fill out a short questionnaire. In addition, I would like to interview both of you personally at your convenience. The interview could be conducted in your home and would take approximately 1.5 hours.

It is recognized that discussing this topic may be difficult for you and that you may feel sad at times. It is my belief, however, that the information gained from the parents who participate in this study will ultimately be of help to other families in your situation.

I would appreciate your consideration of this request. I will be contacting you by phone within the next two weeks . At that time I would be happy to give you more information about the study and to answer any questions you might have.

Sincerely,

Sharon Morgan

APPENDIX E

TELEPHONE STATEMENT

APPENDIX E

Telephone Statement - Sample

"Hello Mrs. Doe, this is Sharon Morgan from the Faculty of Nursing at the University of Alberta. You recently received a letter from me concerning a study on parental grief."

(Assuming the letter has been received.)

"I am calling to see if you have any questions about the letter and if you and your spouse might be interested in participating in the study."

(If the couple indicate an interest I would give the parents a brief overview of my background.)

"The major purpose of the research is to learn about the grief experience of parents over time. In particular, the focus will be on the lasting thoughts and feelings following the loss of your baby, (name, if available)."

"As I indicated in the letter, learning more about this experience will better enable caregivers to be helpful and supportive to bereaved families."

"Before I go any further with details, do you have any questions at this point?"

"I would like to set up a time that is convenient to meet with you. Most parents feel more comfortable in their own homes, but if you would prefer we could meet at the University."

"When we meet, I will ask you to sign a consent form. I will then ask you both to fill out a short questionnaire about past and present experiences related to your loss. After you have completed the form I will interview you and your spouse together - this will take 1 - 1.5 hours. I would like to tape record the interview so that I can accurately document your feelings and ideas. You will not be identified on the tape and once the contents have been analyzed, the tapes will be erased. All information that you share with me will be treated in a confidential manner."

"A second short interview might be necessary to clarify what you have told me. Would that be acceptable to you?"

(At this point I would ask if there are any further questions. I would then confirm time, date and place for the interviews).